Health, Equality and the Economy

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Ulster University

Embracing Challenge
Delivering Change

Health, Equality and the Economy

Edited by Cathy Gormley-Heenan
and Elaine Lackermeier

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Introduction

New Decade, New Approach (NDNA), a new Health Minister for Northern Ireland (the UUP's Robin Swann), a renewed commitment to addressing the plethora of problems within the health and social care system in Northern Ireland coupled with the outworkings and implications of the global pandemic in COVID-19 has meant that this report on health policy and its associated recommendations could not be timelier. The issues facing us do not need rehearsing again. We know the challenges facing health and social care. And as the Department of Health has said, the solutions are also challenging because 'they require sustained investment to address backlogs and build our workforce, as well as the radical reshaping of services'. The funding provided in NDNA does not appear to be enough already.

It is of course important to note that many of the problems we face predated the collapse of the power sharing institutions early 2017. They were not simply caused by three years of a political vacuum, albeit they were exacerbated by it. In the absence of a Health Minister, questions were asked about who was actually setting health policy in Northern Ireland[1]. But there have been plenty of health policy recommendations over the years, so in many ways health policy had already been set. As Birrell and Heenan point out in chapter 1, Northern Ireland has a long history of health reviews and recommendations but implementation has been problematic. The policy direction in these reviews has been consistent, to shift service provision away from hospitals and towards care in the community, as close to home as possible.

We have taken this one step further. Drawing on extensive expertise in the health and social care system from across Ulster University, our report Health, Equality and the Economy sets out what we believe health policy in Northern Ireland needs to focus on, beyond reducing waiting lists, building a workforce and reshaping services away from hospitals towards the community. From our UU Economic Policy Centre perspective, Richard Johnston points out in chapter 2, much of the focus to date has been on healthcare spending, that is, how much more do we need, on what do we need to spend it specifically and over what term?

Professor Cathy Gormley-Heenan, Deputy Vice-Chancellor (Research & External Affairs)

He rightly questions whether more funding will solve the problems and argues that what we must do as a society is to support the hard decisions that increase efficiency, reduce waste and duplication and encourage our citizens to become more responsible users of healthcare services.

The issue of responsible citizenship in healthcare is something that Marie Murphy picks up on in chapter 7. While pointing out that physical inactivity is the fourth leading cause of death worldwide, she notes that Northern Ireland has not had a standalone Physical Activity strategy since the expiration of the Be Active Be Healthy – The Northern Ireland Physical Activity Strategy 1996-2002. She argues that Northern Ireland needs a policy now, one where physical activity can and should be integrated into the environment where people live, work, are educated and play through a cohesive government-led policy with joined up actions created and owned by multiple stakeholders, including the public themselves.

'We know the challenges facing healthcare. The solutions are also challenging because they require sustained investment to address backlogs and build our workforce, as well as the radical reshaping of services'.
Department of Health

Of course, greater efficiencies are made infinitely easier through the mainstreaming of healthcare innovations. As Jim McLaughlin notes in chapter 11, it is now obvious that we are entering into the age of Healthcare 4.0 with challenges that need to be urgently met. Key to these challenges is the upskilling and training of our workforce in the use of digital healthcare technologies. Efficiencies can also be accelerated through a more personalised approach to medicine. Tony Bjourson's chapter 12 emphasises the need to incorporate genomic education as a core component in all clinical education pathways to drive more evidence-based diagnoses, treatments and medicines optimisation.

And these are just a few examples.

Our contributors could have said much, much more, but we've kept it brief for now. Policy briefs should be brief! We look forward to our continued engagement with you and, of course, with our partners QUB and Pivotal on this. The contact details for all of our contributors are included in chapter 15. Do get in touch.

This report was written prior to the arrival of the COVID-19 pandemic. The pandemic has implications for all areas of health policy in Northern Ireland. We have updated the report to include a COVID-19 chapter, where our contributors have set out the COVID-19 context to the issues which they have tackled within the report.

We at Ulster University have asked ourselves the important questions that need to be answered in terms of health policy for Northern Ireland and have presented them here as a series of question-based chapters, reflecting the key issues, key research undertaken and key recommendations for consideration. We've brought these various recommendations together at the end of this report as our contribution to the current policy debate on the future of health and social care policy in Northern Ireland.

[1] BBC NI (2017) 'Health Policy in Northern Ireland - who is Setting It?', Available from: https://www.bbc.com/news/uk-northern-ireland-40371223

The COVID-19 Context

Our Health, Equality and the Economy report was written prior to the arrival of the COVID-19 pandemic. Since then our health and social care system has faced unparalleled challenges. The pandemic has impacted each of our lives and has implications for all areas of health policy in Northern Ireland. In this section, our report contributors have set out the COVID-19 context to the issues which they have tackled within the report.

Health policy in the context of COVID-19

Deirdre Heenan, Derek Birrell

The arrival of COVID-19 in early 2020 delivered a massive shock to an already stressed health and social care system in Northern Ireland. Whilst it is too early to know the full impact of the pandemic, it is clear that there will be long term impacts on the design and delivery of care. Against a backdrop of relatively few ICU beds, crippling staff shortages and low employee morale, meeting the needs of Coronavirus patients has stretched this system to its limits. The rapid reconfiguration of services and resources not only affected patients with Coronavirus but had significant knock-on effects on the care provided to the wider population. In order to free up capacity for patients with the virus, all non-urgent planned surgeries were cancelled or postponed.

In addition to these delays in treatment, demand was substantially suppressed as many patients decided against seeking treatment in order to avoid visiting a hospital. This has resulted in a considerable and growing backlog of health issues, adding to the already dire waiting lists. Prior to the virus, the health and social care system was in an all too familiar state of turmoil, struggling to cope with record demand, soaring costs and the worst ever performance figures including missed targets for A&E care, operations and cancer treatment. Whilst the trajectory for the recovery of the health and social care system is likely to be informed by its position prior to the pandemic, there are opportunities to learn from the responses to this global emergency. It has demonstrated that the health and care system can be agile and responsive, and collaboration can address silos and fragmented service delivery. Decisions were taken at pace and entire hospitals were re-configured. Undoubtedly, there are lessons to be learned and innovations, such as increased use of virtual clinics and telephone triages should be embedded into primary and secondary care going forward. Increased cross-border working has moved up the political agenda and given impetus to the development of mutually beneficial all-island approaches. Significantly, this global healthcare emergency witnessed an unprecedented outpouring of public support and goodwill towards our health and social care services and staff. It is crucial to ensure that this momentum is converted into the political will and strategic vision to make the required, long-overdue changes.

Health inequalities in the context of COVID-19

Goretti Horgan

While the coronavirus was called a great equaliser, evidence quickly emerged that socio-economic inequalities in health profoundly impacted deaths and morbidity from the virus. People in deprived areas living on lower incomes are more at risk of serious illness if they contract the virus but also more likely to live in crowded accommodation and work in low paid jobs which cannot be done from home[1]. There is, of course, nothing new about poor and disadvantaged people being disproportionately impacted in a pandemic.

In Northern Ireland, the majority of deaths among over 75's are in the least deprived parts of the region. While this might seem counterintuitive, it is because there are fewer who live to be over 75 in the most deprived areas. By contrast, the ratio of deaths among under-65s in the most deprived areas is 2.5 times that of deaths in the least deprived areas. The two areas of health inequality discussed in chapter 3, (the impact of air pollution and unequal access to reproductive healthcare) have both featured prominently during the pandemic. Studies have suggested that long-term exposure to air pollution before the pandemic is linked with more severe symptoms from COVID-19 and a greater risk of death[2] [3].

In Northern Ireland Early Medical Abortion (EMA) was provided legally for the first time, ensuring hundreds of women did not have to travel to England during the pandemic. Every other part of these islands permitted EMA to be provided via telemedicine but not Northern Ireland[4].

Severe mental illness in the context of COVID-19

Gerard Leavey

The COVID-19 pandemic and its economic consequences has rendered many of us vulnerable in ways that were once unimaginable. The lock-down and social distancing has undermined much that we take for granted, with damage across every aspect of life, work and relationships. Most of us will have become aware of our own mental fragility due to the loss of social connections, and the sometimes mundane but important structures and activities that provide meaning and purpose to daily life.

Recent evidence indicates that quarantine can produce vulnerability to low mood, irritability, sleep disturbance and aggression. Frontline staff and individuals who have recovered physically may be susceptible to long-term psychological problems. For others, job loss and financial stress combined with employing coping mechanisms such as alcohol misuse is a toxic mix.

In addition to this new wave of distress, people with severe mental illness, who are already among the most socially excluded in our community, will have found quarantine particularly challenging. The characteristics of severe mental illness (e.g. delusions, disorganisation and cognitive problems) coupled with living in shared accommodation and poor physical health leave such people at significant risk of COVID-19.

Historically, mental health services have always been severely underfunded, compared to those for physical health, a substantial inequality that remains unchanged despite years of campaigning. But this must change. Community based psychiatric services have been severely reduced and the voluntary sector organisations will face severe cuts to services unless government moves quickly to provide some financial scaffolding. Compassion and social justice must be central to the much heralded 'new normal'.

Mental health in the context of COVID-19

Siobhan O'Neill, Edel Ennis, Margaret McLafferty

The lockdown measures resulting from the COVID-19 pandemic brought increases in anxiety. Most people adjusted well to the stress of the restrictions. However, for a minority the stress of the pandemic resulted in crisis, stress that was overwhelming, or trauma.

Existing health inequalities were amplified. Those who suffered abuse or lived in poverty were more affected. These individuals were those already at risk of mental illness, and their vulnerability may have been exacerbated. The groups most affected by the virus included people with adversities such as poor physical health, anxiety and depression, and those with lower socioeconomic status.

Experiences of the virus brought physical illness with possible neurological consequences,
but also uncertainty, stigma and isolation from social supports. Restriction of health care interventions may have worsened conditions for many who had mental illnesses. The rituals of grief and bereavement were disrupted. Children and young people were denied opportunities to attend school, play and meet friends at critical stages of their development. Those in deprived areas were worst affected, through factors such as limited access to digital technology and Wi-Fi, and poor outdoor play spaces in high density housing areas. Healthcare staff faced heightened trauma.

We must urgently identify those most affected and provide timely mental health interventions. Protecting people from the economic implications of the pandemic and allowing children and young people to return to the stability of school, with support in place for those who are most at risk, are key elements of the mental health response.

[1] Public Health England (2020) Disparities in the risk and outcomes from COVID19, PHE Publications, London.

[2] Wu, X., Nethery, R. C., Sabath, M. B., Braun, D. and Dominici, F. (2020) Air pollution and COVID-19 mortality in the United States: Strengths and limitations of an ecological regression analysis. Science Advances, 6, p.eabd4049.

[3] Cole, Matthew A et al. (2020) "Air Pollution Exposure and Covid-19 in Dutch Municipalities." Environmental & resource economics, 1-30. 4 Aug. 2020, doi:10.1007/s10640-020-00491-4

[4] Bateson DJ, Lohr PA, Norman WV, et al (2020) The impact of COVID-19 on contraception and abortion care policy and practice: experiences from selected countries, BMJ Sexual & Reproductive Health 2020;46:241-243

Physical activity in the context of COVID-19
Marie Murphy

COVID-19 has had dramatic global effects on almost every aspect of life including physical activity. Lockdown and social distancing have brought significant challenges and opportunities for physical activity and has placed it firmly on the public health agenda.

During lockdown, public health guidance and legislation discouraged people from leaving their home. Notably in the UK, Ireland and elsewhere government messaging promoted physical activity with messages indicating that one of the few reasons people were permitted to leave home was 'one form of exercise a day – for example a run, walk, or cycle' (Boris Johnson, 23 March 2020) or 'to take brief individual physical exercise within 2km of your home' (Leo Varadkar, 27 March 2020)

Emerging evidence suggests that for many, walking and cycling increased during lockdown. Additional free time (from not working or working from home with no commute), a reduction in other leisure time options (sport, gyms, swimming pools) and the promotion of exercise as a justifiable reason for leaving the house (permission to be active) are likely to have contributed to these changes. However, working remotely from home is also to have decreased incidental daily activity including commute and activity during the work day.

For those who get their physical activity from playing sport or through using leisure facilities (gyms, sports clubs, swimming pools), the closures are likely to have decreased physical activity. Likewise school-aged children who gain significant proportions of their daily physical activity at school (curricular PE and extra-curricular sport, break time activity) and in their recreational pursuits (sports clubs, gymnastics class, swimming lessons etc) are likely to have faced greater challenge in achieving or maintaining physical activity. For those considered vulnerable and shielding at home, including adults over 70 years old, the lockdown period is also likely to have decreased physical activity.

As it became clear that obesity and other health conditions were associated with poorer prognosis from COVID-19, there was an increased public health focus on the need to get or keep people active. What also became evident was the mental health effects of lockdown. Given the proven benefits of regular physical activity to good mental health and its capacity to reduce anxiety and depression there has never been a more pressing need to promote physical activity.

Health inequalities in physical activity may have increased during lockdown with the socially disadvantaged less likely to have access to gardens or green space for being active. In this regard, the importance of keeping parks and public spaces open during times of restricted opportunities for physical activity is vital. As the pandemic continues and the possibility of a 'second wave' are considered it is now, more than ever, vital that we ensure people have the knowledge, skills and resources to maintain physical activity during future lockdowns

The pandemic has underscored the need for a joined-up approach for the promotion of physical activity through a bespoke Physical Activity Strategy for Northern Ireland called for in chapter 7.

Social care in the context of COVID-19
Anne-Marie Gray

Social care, and care homes in particular, have certainly been in the spotlight as a result of the COVID-19 pandemic. The deficiencies of the social care systems across the UK during the pandemic have been well documented. These include delays in ensuring adequate PPE provision, the health care of residents in care homes, the discharge of COVID-19 positive patients from hospitals to care homes and the pay and working conditions
of staff.

However, as dicussed in the social care chapter in this report, the pandemic has simply brought into sharp focus the consequences of the neglect of adult social care over many decades. A recent Health Foundation report referred to adult social care as one of the biggest public policy failures of a generation. But this could be a watershed moment for social care. During COVID-19, there has been huge outpouring of support for social care workers from a public that became more informed about what they do and the pressures they encounter on a daily basis.

We also know that previous research, as detailed in chapter 9, shows that the public are in favour of reform of adult social care, including a more universal approach. Ultimately, fundamental and comprehensive reform is needed, including to how social care is funded. The degree of change required cannot be achieved within the current models of health care operating anywhere on these islands. But two areas in particular discussed in this report need urgent attention – the privatisation and fragmentation of the care home sector and the social care workforce.

Care Homes in the context of COVID-19
Assumpta Ryan

Based on data from the Northern Ireland Statistics and Research Agency (NISRA), it is estimated that deaths of care home residents account for approximately half of all COVID-19 related deaths in Northern Ireland. A similar picture has emerged elsewhere. In June 2020, The London School of Hygiene and Tropical Medicine reported that care home residents accounted for over 40% of known COVID-19 deaths in England. Although no assumptions can be made in relation to where or when the disease was contracted, there is no doubt that the pandemic has had a devastating impact on people living in care homes and on the families and staff who support them.

Care homes are people's homes and the transmission of COVID-19 between some of the frailest members of society, many of whom are living with dementia, is especially difficult to prevent. While accepting the vulnerability of care home residents, the impact of COVID-19 underlines the need for care home staff to be given timely and appropriate support to safely and effectively care for residents, particularly those at the end of their lives.

The COVID-19 experience of care homes indicates the need for more accessible financial support, better partnership working between NHS and social care as well as support with staff shortages and in the provision of psychological support to residents, relatives and staff. A well-resourced supply chain of PPE; joined up, timely, and coherent guidance that is feasible to implement in long-term care settings; access to regular and efficient testing for staff and residents and accurate clinical information on hospital discharges are all key to a whole system response that will be required to prevent future avoidable deaths in the event of furtherwaves of the pandemic.

Health Technology in the context of COVID-19
Jim McLaughlin

The COVID-19 pandemic has introduced both challenges and opportunities within the digital health technology envronment in Northern Ireland. Of note, innovations included the introduction of remote clinical e-working, virtual clinics, specialist implementation via expert panels (to introduce systems like Track and Trace and Symptom Checking/Stop Covid-19 App), diagnostic solutions; and modelling including lockdown/relaxation predictions, health and economy implications, and emergency need.

All this has required teams across the academic, business and clinical areas to work collaboratively, show new forms of leadership and embrace the Healthcare 4.0 reforms as highlighted in the Closing the Digital Gap 2019 and NI E-Health 2016 Strategy reports. The importance of robust 'UX designed smart systems' and the utilisation of Artificial Intelligence has received much attention, particularly within validation and trial phases of devices and software to allow high-quality uptake that delivers high-quality decision-making with low false positives/negatives.

COVID-19 has fully tested e-health to the limit, demonstrated the importance of the Electronic Record Systems, shown the need for more and better systems and highlighted the need to improve our standards in relation to logistics, presentation data, robust decision making to help with patient flow and also allow commercial opportunities to develop within the pandemic Living Lab environment.

Our more generic e-health challenges in Northern Ireland have been strongly highlighted in relation to broadband/4G/5G infrastructure, the need for e-prescriptions implementation and the importance of data access to aid emergency pandemic decision as well as develop rapid innovation.

chapter 1

What is the context for health policy in Northern Ireland?

Deirdre Heenan, Derek Birrell

This chapter identifies the key influences which have contributed to current health policy in Northern Ireland and provides a brief overview of the major issues. A series of commissioned reports which have diagnosed problems and made recommendations for change have had a significant impact on the direction of travel. The formulation of health policy in the Programme for Government through the adoption of a performance methodology, Outcomes Based Accountability (OBA) is also summarised.

The broader context of the funding arrangements for health care is briefly outlined and a comparison is drawn with finance and performance in the rest of the UK. Perennial issues such as waiting lists, workforce planning and modernisation are considered. An important contextual background is the structural integration of health and social care in Northern Ireland, resulting in the terminology the HSC in Northern Ireland, as compared to NHS England, NHS Scotland and NHS Wales.

BACKGROUND

The Health and Social Care (HSC) system in Northern Ireland serves a population of 1.8 million. People live in urban, semi-rural or rural communities. Responsibility for population health and wellbeing, and the provision of health and social care, is devolved to the Northern Ireland Assembly from the United Kingdom government in Westminster. As in other parts of the United Kingdom, the Northern Ireland health service operates based on the founding principles of the National Health Service - the provision of care according to need, free at the point of access and beyond, funded from taxation. However, since the advent of devolved government, England, Scotland, Wales and Northern Ireland have adopted their own strategies for: promoting and protecting health; preventing disease; reducing health inequalities; and, planning and providing health and social care services. The countries have developed different structures and functions within their systems to meet these responsibilities. Thus, they vary in features such as: arrangements for planning and contracting of care; levels of investment in public health, primary and community care versus hospital provision; funding models; incentives; use of the independent sector; managerial structures; and, the role of the headquarters function[1].

Northern Ireland requires 9% more expenditure than England to meet health needs.

THE COMISSIONED REPORTS

Independent Review of Health and Social Care in Northern Ireland - Appleby Report (2005)[2]

This review considered funding, use of resources and performance management systems and made recommendations for the separation of commissioning/ purchasing from the provision of services. It was adopting a model from England to sharpen incentives, drive performance and reduce costs and was implemented through the commissioning role of the Health and Social Care Board and the provider role of the five Health and Social Care Trusts.

Rapid Review of the Northern Ireland HSC funding needs and the productivity challenge 2011/12 – 2014/15 - Appleby Report (2011)[3]

A further review of finance and efficiency identified continuing low productivity and raised doubts if purchaser-provider split was working. A calculation was made that Northern Ireland required 9% more expenditure than England to meet health needs.

Transforming Your Care (2011)[4]

This major review of Health and Social Care was critical of how needs were being met and made 99 recommendations for improvements. The major recommendation proposed a shift in provision and resources from the acute care sector to primary, community and social care sectors.

It suggested 10 acute hospitals could be reduced to between 5 to 7 major hospital networks. It strongly recommended enhancing the integration of health and social services.

Right Time, Right Place: Donaldson Report (2014)[5]

This inquiry had an original focus on governance and serious adverse incidents investigations, however, it broadened into a short but wider analysis of problems with Northern Ireland HSC. Donaldson criticised a failure to implement the TYC recommendations, particularly finding that the commissioning system was not working and should be replaced. Another recommendation was the need to strengthen the patient voice.

It also made the interesting observation that Northern Ireland had no established think tank for health and social care.

The Government responded with a commitment to abolish the Health and Social Care Board and its commissioning role, but this has not yet been implemented.

Systems, not Structures – Changing Health and Social Care: Bengoa Report (2016)[6]

This was a very influential report on the configuration of HSC services setting out principles and aims for a future configuration. Bengoa suggested that the benefits of integration had not been fully explored and recommended reinforcing the combined activities of health and social care with a more in-depth integration. The triple aim of better health, quality and value is now well-accepted throughout the UK, however in Northern Ireland Bengoa went one step further.

He advocated the quadruple aim by adding improving the work life for those who deliver care. Attention was drawn to the need to support transformation and promote the integration between health and social care with the intention to reduce emergency care and hospital admissions. The actual model that was recommended was an accountable care system (ACO). Such systems were experimented with in England, but proved controversial and were withdrawn.

Health and Wellbeing 2026 – Delivering Together[7]

This strategy document was a speedy response to Bengoa but had to operate in the context that Bengoa was not a specific blueprint suggesting structural reorganisation.

Delivering Together was focused on four guiding principles:

1. **building capacity in the community and prevention;**
2. **a public health focus;**
3. **providing more support in primary care with practice-based pharmacy and multi-disciplinary teams in GP practice;**
4. **reforming community and hospital services with initiatives such as acute care at home.**

There was no specific recommendation on the configuration of acute hospitals and advocated better management structures including more emphasis on the voice of the patient.

THE INFLUENCE OF OUTCOME BASED ACCOUNTABILITY METHODOLOGY

The Programme for Government prepared by the Executive in 2016 was based on a performance management methodology, Outcome Based Accountability (OBA) which differed from other outcomes-based approaches. OBA required setting desired or imagined outcomes and working backwards to set out a small number of statistical indicators. The draft Programme for Government in 2016 set out 14 outcomes which were very general in nature, each with 5/6 indicators and this was presented as a policy programme. The health outcome was described as "we enjoy long healthy, active lives" with another social outcome "we care for others and we help those in need".

Five indicators were linked to the health outcomes:

1. **healthy life expectancy at birth;**
2. **preventable mortality;**
3. **percentage population with GHQ 12 scores >4, signifying possible mental health problems;**
4. **satisfaction with health and social care;**
5. **gap between highest and lowest deprivation quintile in healthy life expectancy at confidence of population aged 60 years or older**

OBA has been criticised for using vey general or vague projected outcomes and treating indicators as causes. Following the collapse of the Executive, Departments produced a delivery plan based on the outcomes and indicators to be used by a returning Executive. In practice the action plan for health had a focus on health inequalities and improving mental health and patient feedback, but did not produce any policies related to waiting lists, integration, hospital configuration, elective care or emergency care. As well as OBA influencing limited policy development, major resources have been devoted to training the staff of public bodies in the use of the methodology. An assessment of the Outcomes Delivery Plan[8] acknowledged that while the design and delivery of health services is a crucial component in ensuring good outcomes, population health is largely determined by economic, social and environmental factors.

THE TRANSFORMATION OF HSC

The Programme of Transformation has operated through a Transformation Implementation Group (TIG) and although intended to be led by the HSCB is mainly led by the Department of Health. The Programme has operated in two contexts, the lack of adequate funding and the absence of a Minister.

The main components of the transformation programme are:

- Hospital reconfiguration- This is carried out through a networking of services on a specialist location basis rather than any decision on status of hospitals;
- Service configuration reviews have been or are being conducted in areas of: stroke care; cancer care; neurology services; pathology services; urgent and emergency care.

Alongside this, seventeen Integrated Care Partnerships (ICPs) have been established in geographic areas of each of the five trusts. These are non-statutory and consist of representative inter-professional committees to develop projects in the five fields of diabetes, stroke, respiratory illness, the frail elderly and palliative care. Most projects are short term and with approved Trust funding[9]. Projects have evolved to date with a strong community development focus in areas such as social prescribing.

WAITING LISTS

Waiting lists have been a perennial issue for all four countries of the UK over the past decade, with all struggling to meet targets and maintain any previous improvements. Waiting lists in Northern Ireland are by far the worst in the UK. Despite relatively similar approaches to waiting times, large differences have emerged.

Statistics published by the Department of Health[10] reveal a continuing deterioration of both outpatient and inpatient waiting times. All Northern Ireland waiting time targets are currently being breached. Waiting list sizes have also increased and patients are waiting a very long time for treatment. There is increasing concern that this escalating problem is causing significant risk to patients and may result in increased disease and preventable deaths.

The Department of Health figures show that as of 30 June 2019, a total of 299,436 patients were waiting for a first consultant-led outpatient appointment. This is 3.7% (10,682) more than at 31 March 2019 (288,754) and 8.5% (23,552) more than at 30 June 2018 (275,884).

299,436 patients waiting for a first consultant-led outpatient appointment.

35.2% waiting more than a year for a first consultant-led appointment.

Over a third of patients — 35.2% (105,450) — were waiting more than a year for a first consultant-led outpatient appointment, an increase of 5.3% on the same quarter last year (when there were 88,598 patients). The number of people (105,486) waiting over a year for a consultant-led outpatient appointment in Northern Ireland, represented 100 times more than in England, with a population 30 times greater.

WHAT ARE THE CAUSES?

In recent years a number of studies and reviews have identified the key causes escalating waiting lists in Northern Ireland:

- Rising demand due to an ageing population;
- Growing demand in emergency care has meant elective care beds are increasingly being used to care for emergency patients;
- The weaknesses of the commissioning system have also contributed to higher waits;
- A lack of beds has created a growing planned admissions cancellation rate which over the last 12 months on average exceeded 30% (as high as 50%) with many urgent admissions cancelled;
- Workforce issues such as insufficient numbers of doctors, nurses and other health professionals, along with recruitment issues and the historical reliance on expensive agency staff, are widely acknowledged as the key causes of delays in accessing elective care in some specialties;
- The reduction in use of the independent sector, as a consequence of reduced funding for waiting list initiatives over the last 18 months, has had a major impact on waiting times. Historically, the Health and Social Care Board (HSCB) has provided non-recurrent funding for waiting time initiatives through a variety of private care providers, to reduce the numbers of patients waiting for treatment. In 2010/11, the HSC spent around £23m on independent sector treatment. By 2013/14, this had risen to £72m.
- In July 2014, a moratorium was placed in the use of the independent sector due to financial pressures. While the moratorium was lifted and funding released in 2015, it has not been possible to identify the number of patients treated in the sector. This change has nevertheless negatively impacted on waiting times;
- The failure to implement reforms, set out in a series of reviews, has led to a piecemeal approach to service improvement rather than a programme of transformation;
- The political vacuum since January 2017 offers little prospect of immediate relief for anxious patients. The additional funds agreed by Westminster in the DUP/Conservative confidence and supply agreement which were to be targeted at waiting time pressures and support for the implementation of the reform agenda have yet to materialise. With no agreed budget for health, no minister and waiting times deteriorating over every quarter in the last year, HSC Trusts have fought to maintain existing services, with smaller budgets, while being required to make efficiencies;
- Austerity and short-term financial planning.

In his latest report on waiting lists across the four UK nations, Appleby[11] noted that demand for secondary care in Northern Ireland is not significantly higher than in the remainder of the UK that it would explain the huge disparity in waiting times. The setting of a target on its own is insufficient to tackle long waiting lists and indeed the setting of targets depends largely on the system's ability to meet to them. This is dependent on basic factors such as money, management, commitment to organisational strategies and the ability of the system to utilise its budget effectively. It is the variation in these factors that explain the overall worsening performance and the persistent differences between them.

Number of people waiting over a year for a consultant-led outpatient appointment 100 times more than in England.

STRATEGIES TO ADDRESS WAITING LISTS

Extensive research on tackling waiting lists has concluded that policies and strategies have had limited success and generally improvements have proved difficult to sustain[12]. It has been contended that policies based on the erroneous assumption that waiting lists were simply a backlog which could be addressed through a series of short-term ad-hoc interventions and initiatives were doomed to failure. Long-term sustainable reductions in waiting times should be based on a number of key factors. They must meet a level of demand that rises in response to technical change, demography, rising user expectations, and changes in clinical behaviour.

In research for the King's Fund[13], Appleby aimed to ascertain what policies and strategies might prove successful in sustaining reductions in waiting times. This work, based on in-depth interviews with clinicians and managers in nine hospitals, identified a range of factors associated with successful outcomes. The research found that this was a complex issue with no one size fits all solution. However, several factors emerged as significant when achieving and sustaining reductions in waiting times. These were:

- a sustained focus on the task, organisationally and through management and clinical effort;
- an understanding of the nature of waiting lists and how they form part of a whole system of care;
- the importance of detailed information, analysis, forecasting, monitoring and planning;
- the development of appropriate capacity.

Addressing the waiting list in a sustainable way involved rigorous scrutiny of the logistics processes. This involved looking at patients' pathways, attempting to streamline and simplify, identifying bottlenecks and pinch-points for individual patients, and then using the whole-hospital system perspective to work out, for example, the best way of handling the interaction between elective and emergency flows. These large scale strategic interventions were supported by a number of smaller measures to improve efficiency, including the careful management of beds, maximising day-case activity, ensuring the full use of theatres, and effective discharge planning, including investment in convalescent step-down facilities to free up beds for elective cases[14].

WORKFORCE PLANNING

An ongoing issue in Northern Ireland has been poor workforce planning resulting in shortages of key staff groups, a costly reliance on temporary staff, and a misfit between the workers available and those that would be needed if the service were to meet its aspirations to change. The Northern Ireland Audit Office (NIAO) recently counted annual locum doctor spend as £83 million in 2017–18. In November 2019 there were 7,000 vacancies across the system which included 3,000 nurses and midwives (Belfast Telegraph, 25th November). This accounted for more than 10% of all spending on doctors in every area of Northern Ireland. They noted that increasing amounts being spent on employing locum doctors to maintain healthcare services was placing significant strain on already stretched Trust budgets. Despite the urgent need for more strategic, innovative and forward-thinking initiatives to reduce reliance on locum doctors, the NIAO found that the Department and Trusts have made no tangible progress in implementing effective solutions to reduce the heavy reliance on locums[15].

Around 7,000 vacancies including 3,000 nurses and midwives.

In 2018, the Department of Health published a long-awaited workforce strategy[16]. It is a far-reaching and aspirational document, with an impressive level of ambition around bringing new types of staff into the workforce and expanding people's skills. However, it contains little discussion of the exact numbers of key staff groups needed and the exact mechanisms by which these will be secured. A process to come up with indicators is mentioned, but it is unclear how this will be achieved.

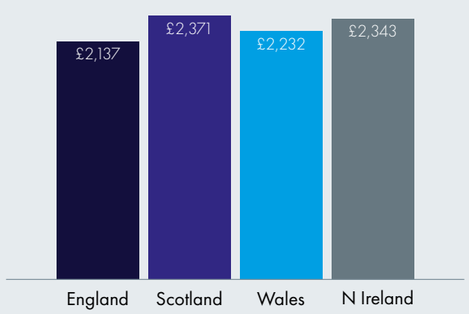
FINANCE

Health and social care funding is the single largest area of public expenditure in Northern Ireland. In 2016-17, the total budget, was £4.9 billion, accounting for 46% of the Executive's overall budget. Some £3.6 billion of this (73%) was allocated to the Health and Social Care Board (HSC Board) and Public Health Agency (PHA) to commission services from the HSC Trusts (the Trusts) and other bodies (NIA, 2018)[17].

Funding for the HSC comes mainly through the Barnett Formula which is calculated substantially on expenditure in England and a population basis. The Northern Ireland Office (NIO) has discretion to allocate Barnett funding to meet locally determined priorities. Currently Northern Ireland expenditure per capita on health is not so different from other countries of the UK and is lower than in Scotland. The Department has expressed the view that health and social care trusts face a £20 million deficit and cannot afford to do more things with the fixed budget.[18]

Some additional resources for health have been made available through the DUP Confidence and Supply Agreement. It would also be possible to invest more in health through either efficiency gains, reducing expenditure elsewhere or increasing revenue from the regional rate or new taxes.

Expenditure per capita 2017/18[19]



HSC funding single largest area of public expenditure in Northern Ireland.

DECISION MAKING, MANAGEMENT AND GOVERNANCE

A key question in terms of health and social care in Northern Ireland is, are the existing structures fit for purpose? Following the devolution settlement, health and social care became a single relatively large Department, overseen by one government Minister. This is markedly different from the administration in Scotland and Wales. Additionally, in England the permanent secretary is not the head of the NHS. Given the challenges associated with this portfolio, it may perhaps be timely to consider alternative arrangements.

In his study comparing the NHS across the four nations of the UK, Greer[20] suggested that the management style in Northern Ireland was top-down and centralised. He referred to the system in Northern Ireland as a permissive management style which was markedly different from the markets approach in England, localism in Wales and professional elite system of Scotland. Within Northern Ireland delivery and decision-making in healthcare rests extensively with quangos with a substantial number of non-executive nominated members whose role is unclear. It is also difficult to ascertain if and how these nominated members represent user groups.

In his 2014 review of the Northern Ireland Health Service, Sir Liam Donaldson memorably observed that the people he interviewed had no consistent answer as to who was in charge of, or ran, the health system. He suggested that abolishing the commissioning body, the Health and Social Board, would reduce complexity and cut administration costs. In 2016, the then Health Minister announced plans to abolish the body with associated savings of approximately £30 million per annum. To-date though this body still exists and future plans for it are unclear. However, in their review Heenan and Dayan[21] found a markedly different picture with a broad consensus that health and social care was run by the Department of Health with an almost vice like grip. Both reviews commented on the very traditional and quite bureaucratic management model. This emphasis on centralised control can greatly disempower those working at the local level and was thought to impede change. The alternative is a style of shared leadership based on inspiration, motivation and trusting those working in the system to make good judgments and innovate as appropriate.

POLICIES AND MODERNISATION DEBATE

Northern Ireland has been relatively slow to adopt a number of GB policies and strategies around the modernisation and transformation of the health and social care policy arena. Key policies and agendas include:

- Personalisation - to date in NI there has been relatively limited use of direct payments or individual budgets;
- Co-production - this remains underdeveloped in terms of participation in the decision-making process, compared with NHS Foundation Trusts' governance arrangements;
- Hospital reconfiguration - proceeding with recommendations to reduce numbers of acute hospitals.

CONCLUSION

Northern Ireland has a long history of grand reviews with the reality falling well short of expectations. The policy direction in these reviews has been consistent, to shift service provision away from hospitals and towards care in the community, as close to home as possible. The challenges facing health and social care are well documented. The last government agreed with the need for **radical change**, as envisioned by various experts, yet progress has been slow and uneven. There is a need to **transform services** in a way that builds on the **integrated system** of health and social care and joins the dots to the wider healthcare system. The most recent political vacuum has created a huge hiatus in health, but many of the problems in the system are enduring and pre-date the collapse of the devolved structures. Waiting lists in Northern Ireland are substantially worse than in the rest of the UK, this is not simply a backlog in the numbers of people waiting for care but reflective of systemic failings in health and social care. Northern Ireland's performance figures are dire with few if any strategies designed to address these issues.

In these times of heated debate about the future of health and social care in Northern Ireland and the doomsday stories that abound about its imminent collapse, it is crucial to understand how the system performs as a whole and how it can be improved. Having a clear framework for characterizing what is, and isn't, **evidence-based** health policy is a prerequisite for a **rational approach** to making policy choices, and it will help to focus the debate on the most **promising approaches**.

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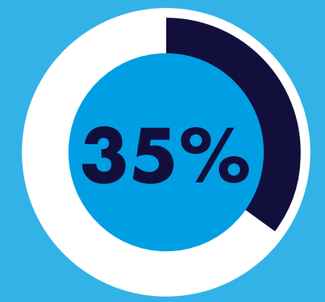
NORTHERN IRELAND REQUIRES

9%

MORE EXPENDITURE THAN ENGLAND TO MEET HEALTH NEEDS



WAITING MORE THAN A YEAR FOR A FIRST CONSULTANT-LED OUTPATIENT APPOINTMENT

299,436

PATIENTS WAITING FOR A FIRST CONSULTANT-LED OUTPATIENT APPOINTMENT.

NUMBER WAITING OVER A YEAR FOR CONSULTANT-LED OUTPATIENT APPOINTMENT

100

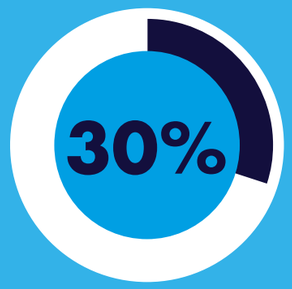
TIMES MORE THAN ENGLAND

ANNUAL LOCUM DOCTOR SPEND REACHES

£83

MILLION

PLANNED ADMISSIONS AND CANCELLATION RATE EXCEEDS



AROUND

7,000

VACANCIES INCLUDING

3,000

NURSES AND MIDWIVES

SINGLE LARGEST AREA OF PUBLIC EXPENDITURE IN NORTHERN IRELAND

Chapter 2

What is the cost of healthcare in Northern Ireland?

Richard Johnston

The healthcare system in Northern Ireland has reached a critical point. An increasing population, longer life expectancy, more complex and interrelated healthcare requirements are placing more demands on the health service than ever before.

Waiting lists far exceed those in other parts of the UK and Ireland, and nurses took industrial action for the first time in 103 years. Unfilled vacancies present a serious challenge and the reliance on temporary staff to fill permanent posts is an inadequate long-term strategy. In terms of remedies, much of the focus so far is on healthcare spending - how much more, on what and over what term? But will more funding solve the problems?

What we must remember in these debates is that each pound spent is either a pound of taxpayer's money or a pound borrowed by the UK Government, which represents a cost for future generations. Someone will pay for the public services that we demand as a society, either now or later.

There are always more demands on public services than available resources and it is an unenviable task for those attempting to satisfy as many of those demands as possible within the budget granted to them. The question that we must ask ourselves is whether taxpayer's pounds are being spent in ways that deliver the best value?

Nurses take industrial action in Northern Ireland for the first time in 103 years.

COSTING PUBLIC SERVICES IN NI

In 2018/19, public services in NI cost £29.1bn to deliver.[1] As a society, we paid £18.5bn in taxation, resulting in a fiscal deficit of £10.6bn in NI. On a per capita basis, NI has the highest level of public spending per capita – close to £15,500 per person annually. We should pause to think about the challenge that figure presents. All of the road, rail and technological infrastructure, education, policing, justice, healthcare demands and much more - must be delivered within this budget envelope. This is a significant challenge in itself for public servants and politicians.

[1] Source - Department of Finance. Figures include the accounting adjustment of £3.2bn (such as funding Government borrowing) and NI's contribution to UK non-identifiable expenditure of £2.9bn (these include defence etc which are shared out across the UK regions on a per capita basis).

Public services in Northern Ireland cost over £29 billion to deliver.

THE HEALTHCARE BUDGET - A RAPID GROWTH PRIORITY

The NI Executive has devolved control of £12.3bn of the budget, which is referred to as Departmental Expenditure Limits (or DEL). The remainder of expenditure is on matters that are reserved for Westminster and include items such as pensions and benefits. These are referred to as Annually Managed Expenditure (or AME) of £10.1bn plus the accounting adjustment and non-identifiable expenditure noted above.

The Department of Health was allocated £6.1bn in 2019-20, which is half of the available DEL budget. The rate of increase in spending is rapid; 6.8% per annum, or £1.1bn more being spent annually than three years ago. It is the largest and fastest growing area of expenditure that is within the control of the NI Executive, demonstrating the priority that is given to healthcare. Other Departments have increased spending at more modest rates and two (Communities and Economy) have reduced expenditure, which will have helped to fund the increase in healthcare spending.

SPENDING MORE THAN THE UK AVERAGE

NI spent £2,306 per person in 2017-18 on healthcare, which is less than Scotland, similar to Wales and more than the UK and English averages. On that basis, it would be reasonable to expect similar outcomes to Wales, but this is not the case in terms of waiting lists, mental health spending or unfilled vacancies. This would suggest that additional funding is one aspect of the solution, but reform and efficiency savings are the other side of the same coin.

FOCUSSING ON SOLUTIONS

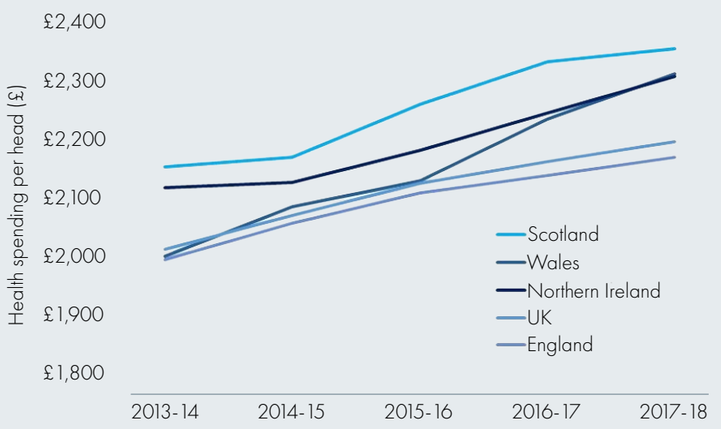
The draft Programme for Government (2016-21) focussed on improving wellbeing for all as the key priority for Government. The Department of Health's budget allocation is the largest of the NI Departments and has increased more rapidly than any other in recent years. It is clear that healthcare is the priority, as illustrated by the scale of expenditure and rate of growth.

NI's population is both growing and aging. With that comes increasing demands on the healthcare sector in terms of dealing with illness and interrelated and complex healthcare needs. It is clear that demands are only going to continue to increase. However, we must focus on the fact that every pound is someone's pound, there is no source of "free" money and therefore we have an obligation to ensure that we do our best with the available budgets.

IMPLEMENTING REFORMS

In terms of reform, the Bengoa report and others provide a road map of the reforms that are necessary. Beyond that, we must think more radically about what we would be prepared to make do with less of, in order to fund increasing healthcare requirements. Alternatively, would we be willing to pay more in rates? How would domestic ratepayers or businesses react? After all, it is those who lose services or are required to pay more in taxation that are likely to be the most vocal. Our tax policy stance is an area for discussion – we may wish for Scandinavian levels of public service, but they come at a price that is more than what we are currently paying. This will be one of the key issues for NI's Fiscal Council to consider when it is created later in 2020.

Identifiable Expenditure per capita on healthcare (£), UK countries, 2013-14 to 2017-18



Source: Public Expenditure Statistical Analysis

£2,306 spent per person on healthcare.

USING TECHNOLOGY BRILLIANTLY

Automation has played a significant role in boosting private sector productivity and in general, reducing the cost and increasing the quality of a range of goods and services. There are, as yet, potentially unexploited gains to be realised in NI. Big data, wearable technologies and the Internet of Things all provide opportunities for rapid progress in the healthcare arena. Research now proves that Artificial Intelligence can outperform doctors at diagnosing certain cancers and fractures. Faster and more accurate diagnoses can reduce costs and complications and it will be imperative for the healthcare sector to become a rapid adopter of new technologies, something which is a challenge for large public sector organisations.

NUDGING IN THE RIGHT DIRECTION

Alongside the increased use of technology, there is a better understanding of human behaviour and how behavioural economics can be used to help healthcare consumers make better choices that can ultimately reduce the cost of healthcare delivery. For example, evidence shows that sending a text saying that every missed appointment costs the Health Service £160 resulted in a 25% reduction in missed appointments as people realised the implication of failing to turn up. This is just one simple example, but there are many others that could be employed.

BE GRATEFUL FOR OUR STARTING POINT

We should also be careful not to lose sight of the fact that some of the problems that we discuss here are, in both relative and historical terms "good" problems to be dealing with. Longer life expectancy is to be celebrated, low infant mortality and high immunisation rates are all successes. Therefore, let's face into the challenges safe in the knowledge that it is from a strong foundation and do our best with the resources at hand.

MONEY MATTERS, ALONGSIDE SO MUCH MORE

The clear conclusion of this short article is that the demands on the healthcare sector are increasing and progressively more complex, a trend that is likely to continue over the next few decades. Funding has increased significantly but continuing to roll out the existing form of healthcare to a larger population is unrealistic, unless it is funded by large tax or borrowing increases. Additional funding will help to solve some of the challenges in the immediate term, but it is the implementation and delivery of a long-term sustainable strategy that is required for NI.

£160 cost to Health Service for every missed appointment.

STARK CHOICES

Implementing reforms and boosting efficiency will undoubtedly mean closures or reductions in certain services and in specific geographies. Tough decisions will be required in terms of the location of these services on a regionally balanced basis, indeed we may need to spend more to balance services across NI for the good of society. The UK government has floated the idea of newly trained doctors being tied to working in the NHS for four years or being asked to repay the cost of their training (which exceeds £220k). The British Medical Association and junior doctors are quite understandably, unhappy with the suggestion. Other questions include the value that the public sector might place on resources used in private practise. These are obviously very emotive subjects but are based on the principal of those who use the resources paying for them until the cost to taxpayers is balanced. For context, the recent and very welcome pay parity announcement by Minister Swann will cost c£109m per annum, which exceeds the annual budget of the NI Ambulance service, or would add more than £100 to every domestic ratepayers bill if the revenue was to be raised locally. These are tough decisions with clear budgetary implications.

In closing, what we must do as a society is to support some of these hard decisions that increase efficiency, reduce waste and duplication and encourage our citizens to become more responsible users of healthcare services.

There is no "silver bullet", however, open conversations, robust evidence-based policy making, application of technology, better data and informed user choices can help to improve healthcare services and outcomes for society alongside higher levels of funding. How we adapt and make best use of this new environment during the 2020's will determine our fortune in the longer term.

Training costs over £220,000 for every new Doctor.

NURSES TAKE INDUSTRIAL ACTION FOR THE FIRST TIME IN

103 YEARS

COST TO THE HEALTH SERVICE FOR EVERY MISSED APPOINTMENT

£2,306

SPENT PER PERSON ON HEALTHCARE

PUBLIC SERVICES IN NORTHERN IRELAND COST OVER

£29 BILLION TO DELIVER

TRAINING COSTS OVER **£220,000** FOR EVERY NEW DOCTOR

RATE OF SPENDING INCREASES BY **6.8%** PER ANNUM

NORTHERN IRELAND SPEND PER CAPITA EXCEEDS **£15,000**

Chapter 3

Why are there still health inequalities in Northern Ireland and what needs to be done?

Goretti Horgan

KEY ISSUE

While there have been remarkable improvements in health over the last century, these have not been experienced equally. People's health continues to be influenced by the circumstances of their birth, their childhood, what they earn, where they live and work.

Health inequalities originate from inequalities in vulnerability and exposure to health risks by social groups—both between and within countries.[1] Across varying measures of social standing— including level of education, occupation, or income – those who are more socially advantaged are likely to live longer, and in better health, than individuals from lower socioeconomic backgrounds.

Here in Northern Ireland, this means that while male life expectancy at birth has continued to improve, men living in the most deprived areas of the region are likely to die seven years before their counterparts in the least deprived, while the inequality gap between women in the most and least deprived areas is 4.5 years.

Figures for Healthy Life Expectancy (HLE) and Disability Free Life Expectancy (DFLE) over the same period are even worse: women and men in the least deprived areas are likely to have over 14 years more healthy years of life than those in the most deprived areas.[2]

Increasingly, health inequalities are analysed within the context of the United Nations Sustainable Development Goals (SDGs) which were endorsed by 193 countries, including the UK, at the Seventieth United Nations General Assembly in New York, September 2015. The SDGs are based on the principle of advancing equity and leaving no one behind in the process of economic, social and environmental development. All of the goals are inter-connected and each needs to take account of the other in working to meet targets.

This chapter looks at two areas of growing concern which the SDGs identify as contributing to overall health inequalities and which have received relatively little attention here in Northern Ireland. These are inequalities in the impact of air pollution on health and inequalities in access to sexual and reproductive health care. As with all concerns of the SDGs these inequalities intersect to exacerbate overall health inequalities.

9 out of 10 deaths from air pollution are in low and middle income countries.

Even a brief exploration of these issues explains why in order to achieve the health-related targets of the SDG agenda, contained in SDG 3 the "SDGs require concerted efforts across diverse stakeholders within and outside the health sector to achieve improvements in the many conditions that affect health and the opportunity for health, such as poverty, gender discrimination, lack of educational opportunities, degradation of the natural environment and poor working conditions".[3]

KEY RESEARCH

Impact of air pollution on health inequalities

Ambient (outdoor) air pollution is a major environmental health problem, estimated to cause 4.2 million premature deaths worldwide per year in 2016; this mortality is due to exposure to small particulate matter of 2.5 microns or less in diameter (PM2.5), which cause cardiovascular and respiratory disease, and cancers. While such pollution impacts everyone in low-, middle-, and high-income countries, there are major inequalities between and within countries in relation to exposure to, and impact of, air pollution. The World Health Organisation estimates that 9 out of 10 deaths from air pollution are in low and middle income countries, but this does not mean that those of us living in rich countries like the UK or Ireland need not be concerned. Indeed, in the WHO list of countries and cities in Europe that have fine-particle air pollution levels above 10 micrograms per cubic metre, the UK features large, with 30 cities having levels above that limit. Derry-Londonderry is one of those cities, with the same air pollution level as London.[4] Here in NI, high levels of exposure to oxides of nitrogen, including ammonia, are as concerning as are levels of fine particulates. NI has the highest levels of ammonia emissions in the UK. The agriculture sector contributes 94% of all ammonia emissions in NI. In very low concentrations, ammonia is not harmful to human health. However, when ammonia emissions combine with pollution from industry and transport (for example diesel fumes) they form very fine particulate matter (PM2.5), which can be transported significant distances.

Chronic exposure to higher levels of fine particle matter have been found to impair vascular function, "which can lead to myocardial infarction, arterial hypertension, stroke, and heart failure".[5] It is notable that in a very large population-based cohort with up to 25 years of follow-up, small particulate matter was associated with mortality at concentrations as low as 5 micrograms per cubic metre, which is half the limit recommended by WHO.[6]

Evidence linking air pollution to non-infectious respiratory diseases is even stronger. Exposure to various air pollutants has been related to asthma, chronic obstructive pulmonary disease (COPD), and lung cancers. Systematic reviews and meta analyses have shown that air pollution is related to mortality, hospitalisation and A&E visits in patients with COPD.[7,8]

Pfeffer et al[9], using data from the London COPD Cohort, followed for 20 years, showed a consistent association between higher levels of nitrogen oxides and an increased incidence of COPD exacerbations.

The agriculture sector contributes to 94% of all ammonia emissions in NI.

Both in relation to cardio-vascular and respiratory conditions, the impact of air pollution on health differs according to socio-economic conditions. In Northern Ireland in 2016/17, for example, the percentage gap in the standardised hospital admission rates for respiratory conditions, between residents of the most deprived areas and the least deprived areas is 93%. When we look only at under-75 year olds with respiratory conditions, the gap rises to 113%. These gaps have increased since 2013/14.

Reproductive Health

Air pollution is closely associated with reproductive health, especially healthy foetal development. For example, meta analyses have found that maternal exposure to fine particulate air pollution increases the risk of preterm birth and term low birth weight[10]. Systematic reviews also found statistically significant associations between prenatal exposures to oxides of nitrogen and fine particulates and the risk of wheezing and asthma development in childhood[11]. There is also some evidence that infant mortality rates are increased as a result of exposure to air pollution.

For example, when the government of China piloted interventions to reduce air pollution, infant mortality fell by 20% in the two cities chosen for the interventions.[12]

Reproductive health inequalities have been researched by Ulster University researchers in recent years, partly in response to SDG 5 on promoting gender equality, to the Convention on the Elimination of Discrimination Against Women (CEDAW) and to growing calls from civil society for policy development in relation to sexual and reproductive health. Since 2015, researchers have explored access to contraception and abortion in NI; the results indicate clear inequalities between Britain and Northern Ireland and within the region.

Researchers have explored access to contraception and abortion in NI; the results indicate clear inequalities between England and Northern Ireland and within the region.

Because the 1967 Abortion Act was never extended to NI, women seeking abortions here have had to travel to Britain to end unwanted pregnancies[13]. There has long been a concern that access to abortion services in Britain was available only to those with higher incomes, but it was impossible to access any data to confirm or negate that view. But the introduction of free NHS abortions in England for women from NI seems to have confirmed that this was, indeed, the case. Department of Health statistics for April to June quarter of 2018 showed the number of women from NI having (now free) abortions in that quarter was 66% up on the same quarter in 2017, when they had to be paid for privately.

However, our ESRC-funded research with women who used abortion pills obtained over the internet found that some women, particularly those in low paid or precarious employment, with caring responsibilities, or in controlling or abusive relationships are unable to travel.[14] Even with the availability of free NHS terminations, they said they preferred to self-manage their abortion with pills – even at the time that prosecutions were underway of women found to be doing so.

While inequalities in relation to abortion are public knowledge, those relating to contraception have only recently been revealed. Given et al[15] examined the use of prescribed contraceptives in NI and how this varies according to a woman's age and the deprivation in the area in which she lives. This is the first population-based study to explore contraceptive use in NI and includes 560,074 females, aged 12-49 registered with a GP (2010-2016), contributing 3,255,500 woman-years of follow-up.

Just over a quarter of women of reproductive age were using prescribed contraceptives in any one year.

In keeping with figures for GB and Ireland, just over a quarter of women of reproductive age were using prescribed contraceptives in any one year. The greatest users were aged 20-24 with those less than 16 least likely to have a contraceptive dispensed. There was no evidence that the level of deprivation in the area in which the woman lived was related to her use of prescribed contraceptives. However, after adjustment for patient and other practice characteristics, practices operating in the least deprived quintile prescribed 6% more contraception.

The study found that the combined oral contraceptive (CoC) pill and progestogen only pill (PoP) were the most frequently dispensed methods of contraception and, in the years examined, there was a decrease in dispensation of the CoC in favour of an increase in the PoP. It is important to note that typical failure rates of these methods are 9%, compared with long acting reversible contraceptive (LARC) methods such as the progestogen-only implant 0.05% and levongorgestrel intrauterine contraception 0.2%.[16]

The contraceptive methods dispensed varied with the deprivation in the area in which the woman lived. In the least deprived quintile, Emergency Contraception (EC) was dispensed 20% less and the contraceptive injection 12% less compared to the most deprived quintile. Conversely there was 5% greater rate of use of the CoC in the least deprived quintile compared to the most deprived quintile.

As we can see, access to LARC is limited. This makes little economic sense since contraception is considered the single most cost-effective intervention in healthcare.[17] Public Health England estimates that every £1.00 invested in the provision of contraception achieves a £9.00 saving across the public sector.[18]

KEY RECOMMENDATIONS

There is currently a unique opportunity to develop an integrated sexual and reproductive health service for Northern Ireland that can **reduce gender inequalities** while **enhancing protection** of women and children's health. The decriminalisation of abortion in the region means that a new service will have to be developed. ARK (NI's social policy hub, a partnership between UU and QUB) held a series of roundtables with doctors and midwives to explore what kind of service would be best.

The health professionals agreed that a **community-based** integrated sexual and reproductive service, such as that in Scotland where women can self-refer and receive an appointment within a few days is needed.[19] Women accessing an Early Medical Abortion (EMA) in Scotland are able to obtain LARC methods such as implants or progestogen-only injections at the same appointment where they are receiving their abortion medication was emphasised. A **fast track** appointment is made for those women who choose an intrauterine method.

That this is seen as very important to those seeking abortions emerged clearly from the comparative study of women in Northern Ireland and those in Scotland who were self-managing abortions.[20] Health professionals and women both say an **integrated service** would work best to **reduce inequalities** and ensure that more disadvantaged women are able to access LARC methods of contraception as well as EMA.[21]

The World Health Organisation points out that policies in favour of public transport, energy-efficient homes, clean power generation, industry and better municipal waste management would reduce key sources of outdoor air pollution measures and would help meet SDG goals in relation to health, gender and climate change. Stormont Ministers could make a **real contribution** to narrowing the health inequalities gap by adopting policies that reduced air pollution. The easiest way to do this would be a programme of massive expansion of public transport, particularly investing in electrified rail, which would also promote **economic development** across the region.

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Chapter 4

How can we build supportive environments for people living with severe mental illness in Northern Ireland?

Gerard Leavey

KEY ISSUE

Over the past decade, parity of esteem between mental health and physical health services has become a significant policy issue in the United Kingdom but with little evidence that the life chances of people with mental illness has improved. While mental illness carries 22% of the total healthcare burden, it only receives 12% of the health care budget.

People with severe mental illness (SMI) die much younger than the general population[1]. In part, this is due to high rates of suicide among people with SMI.[2,3] Additionally, they are vulnerable to poor physical health including obesity, type 2 diabetes and CHD.[4,5] Some of these problems are associated with anti-psychotic medication and lifestyle behaviours such as unhealthy diets, cigarette, alcohol use and high levels of physical inactivity. Developing new approaches to suicide prevention in this population and increasing the strength and long-term effectiveness of lifestyle interventions of people with SMI is a public health priority.[6]

Bolstering existing and natural support systems may improve long- term effectiveness of lifestyle interventions in this population. This paper will review some of the barriers to improving the lives and longevity of people with severe mental illness. We will then make key recommendations on where and how changes can be made and who should make them.

People with severe mental illnesses such as bipolar disorder or psychosis are at particularly high risk of suicide.

Weight gain and obesity are major problems for people with mental illness.

KEY RESEARCH

People with severe mental illnesses such as bipolar disorder or psychosis are at particularly high risk of suicide[7,8]. This population has particularly poor physical health as a result of medication side effects, lifestyle-related risk factors and socioeconomic determinants[9]. The high prevalence of smoking, alcohol and substance misuse and other lifestyle-related risk factors, contributes to a 15–20-year gap in life expectancy among people with severe mental illnesses.[10,11] Despite this, people with severe mental illnesses are less likely to receive medical care preventive care, such as routine cancer screening.[12,13]

The substantial costs to the health system and the wider economy caused by smoking, obesity, physical inactivity, alcohol misuse and substance abuse are well established.[14,15] For example, smoking rates among people with a mental illness are three times higher than among the general population.[16,17] People with severe mental illnesses (SMI) who smoke are just as likely to want to quit as the general population, but tend to be more addicted and experience greater barriers to quitting.[18] Similarly, weight gain and obesity are major problems for people with severe mental illness, some of which can be attributed to psychotropic medications[19], increasing the risk of developing diabetes or cardiovascular diseases, and contributing to low quality of life[20]. Other interwoven and modifiable risk factors associated with the poor physical health of people with SMI include low self-esteem, unemployment and social exclusion, the low expectations of others and cultural reinforcement within psychiatric settings[21]. Thus, they are much less likely than the general population to engage in vigorous activity and exhibit more sedentary behaviour.

While recent UK policy *(Choosing health: making healthy choices easier)*[22] sets out key principles to help the public make informed choices about lifestyles, there is a lack of evidence on the development of effective interventions to help people with SMI. A recent Cochrane Review on health advice for people with SMI found only limited evidence that physical healthcare advice alone can improve health-related quality of life and that more work is needed in this area[23].

Our own research highlighted the need for a whole system, multidisciplinary approach to improving the physical health of people with SMI[24]. Thus, psychiatric institutions and community-based settings can foster a sub-culture in which the heavy consumption of soft drinks, cigarettes and fast food form a significant, and rarely challenged, element of social exchange.[25]

THE COMMUNITY AND VOLUNTARY SECTOR

While Voluntary sector organisations (VSO) have considerable contact with service users (SU), public health policies related to VSO appear to neglect the role of VSO in physical health care.[26,27] Choosing Health[28] highlighted the need for VSOs and carer involvement on health improvement programmes but offered no particular action or recommendations. Recent policy such as 'No health without mental health' framework[29] suggested a central role in health improvement for local organisations. Recent policy documents such as Closing the Gap[30] only notes the potential need for family and community involvement. In Northern Ireland, the VSO, local organisations and national charities provide much of the community-based care, there are no obligations on such agencies to achieve improvements in physical health. Moreover, regulatory bodies lack policy to ensure VSO staff are trained and confident in health promoting activities. Research suggests that staff attitudes and beliefs are vital to health and lifestyle behaviour change[31].

Supported housing refers to programs that provide access to community-based housing and flexible services to address clients' health and psychosocial needs and may be an ideal setting to deliver healthy lifestyle programs for several reasons[32]. First, based in the community and often managed by VSO, they are less stigmatising than hospital programmes. These agencies already deliver group-based services (e.g., social clubs, educational classes) and have a broad reach in that they serve people with a range of psychiatric diagnoses and health conditions.

Additionally, supported housing agencies in the UK increasingly train and employ peer advocates; therefore, a peer-led healthy lifestyle intervention provides an economically feasible approach that fits with their existing staff. Last, clients have strong preferences for bringing peer-led healthy lifestyle interventions into these agencies' settings[33].

The high prevalence of smoking, alcohol and substance misuse and other lifestyle-related risk factors, contributes to a 15-20 year gap in life expectancy among people with severe mental illness.

FAMILY INVOLVEMENT

Family involvement in mental health services range from the provision of general information on the mental health service and assessments to family psychosocial and educational interventions and therapies. International policies and good practice guidelines highlight the need for families to be supported and actively involved in psychiatric services. Thus, families can encourage adherence to treatment[34], recognise and respond to signs of relapse and assist help-seeking, generally and times of crisis[35]. Their importance cannot be underestimated; one meta-analysis showed that the relapse rate in schizophrenia can be reduced by 20% if relatives of schizophrenia patients are included in the treatment. If family interventions continued for longer than 3 months, the effect was particularly marked[36]. Unfortunately, caregivers are not routinely involved as collaborators in care and commonly report being ignored by services[37], often under the pretext of patient confidentiality[38]. This disjunct is particularly problematic during times of crisis[39]. In our research on families bereaved by suicide, families reported being excluded from decision-making processes in primary care and/or being left to cope alone by services following hospital discharge[40]. The devaluation of family perspectives by clinicians led to delays to appropriate intervention. Poor service contact and the lack of information on "danger signals" or how to manage, places families in a difficult and invidious position.

Moreover, many formal and informal caregivers think of smoking and poor diets as compensatory and/or relatively insignificant in comparison to mental illness symptoms and social exclusion. For example, cigarette smoking is often assumed by caregivers as a coping strategy, a way of alleviating psychiatric symptoms or asserted as a 'human rights' issue[41]. Social isolation, low self-esteem and stigma contribute to the reinforcement of these behaviours.[42,43] Additionally, family members and other informal caregivers let the psychiatric diagnosis and symptoms 'overshadow' the need for physical health care; unwittingly, some families may collude/assist in unhealthy patient lifestyles[44].

The relapse rate in schizophrenia can be reduced by 20% if relatives of schizophrenia patients are included in the treatment.

LIFESTYLE INTERVENTIONS

Promoting initial engagement and then supporting the maintenance of physical activity offers a possible adjunctive intervention which may improve both physical and mental health outcomes in people with SMI. Thus, 150 minutes of moderate-to-vigorous activity per week can increase fitness, reduce positive and negative symptoms and improve cognition.[45,46] Other evidence suggests that vigorous exercise can distract from auditory hallucinations and adverse beliefs and assist them in reality orientation.[47] Furthermore, exercise may improve negative symptoms and real-world orientation. Lifestyle interventions adapted to persons with serious mental illness show promise in reducing weight loss and some risk factors for metabolic syndrome.[48] Evidence suggests that while people with SMI wish to increase their physical activity and improve health , the barriers to participation are mainly associated with low mood and stress, and lack of support[49].

Other evidence indicates that informational/promotional materials are insufficient to engage this population in regular exercise. Thus, motivational interventions that highlight the benefits of physical activity are needed[50]. When combining physical activity consultations with nutritional information using implementation intention prompts, (and plans for action) in small group sessions physical activity and wellbeing can increase in obese and overweight populations[51]. These types of interventions should be professionally designed and delivered leading to effective adherence and longer-term improvement to physical fitness. Additionally, autonomy and social support were identified as critical factors for effectively engaging people with first-episode psychosis in moderate-to-vigorous exercise[52] while past research indicates that scant attention is paid to the role of influential others and a safe and comfortable environment.[53]

KEY RECOMMENDATIONS

- Families provide most of the care and shoulder the greatest burden. If families assume much of the responsibility of managing care and support of people with SMI, it seems sensible and fair that they are **fully equipped** to do so, including being informed about the challenges of caring and provided with **easier access** to advice and emergency services. This can be done through community and voluntary services, primary care and/or mental health services. **Multi-disciplinary teams** within primary care make this provision more possible.
- While it is crucial that the 'insider' knowledge of families is brought into the decision-making process, caregivers must also be **better informed** about the physical health needs associated with SMI and how to assist in adopting **health-promoting behaviour**. This can be done through community and voluntary services, primary care and/or mental health services.
- **Family engagement** with health improvement interventions can be improved if barriers or concerns about the treatment are addressed early, and motivational interviewing is provided to highlight the perceived benefits of participation which although targeted to clients, may additionally benefit relatives.
- People living with severe mental illness should have their physical health needs met by regular physical care assessments. Importantly, physical health and healthy lifestyle promotion should be provided across all sectors. While assessment within primary care is important, the voluntary and community sectors must be engaged in health promotion and incentivized to promote good physical health among their service users.[54]

To summarise, prolonging the lives of people with severe mental illness and improving the quality of the lives thus extended, requires more strongly **integrated services** and interventions. This does not require radically new and expensive systems of care but rather, **improving the existing environments** and **support systems** within the community. Families, the voluntary and community sectors, and primary care are central to this change.

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Chapter 5

What should we do about transgenerational trauma in Northern Ireland?

Siobhan O'Neill, Edel Ennis and Margaret Mc Lafferty

KEY ISSUE

Northern Ireland's history of violence has resulted in high rates of mental illness, and trauma related mental illness among those who were exposed to the Troubles.[1,2,3,4]

The generation who were worst affected are now parents and grandparents, however the rates of mental illness and suicide in young people who did not directly experience the conflict are high.[5] There is therefore concern that we are seeing the effects of transgenerational trauma. Trauma may be passed from one generation to the next through its impact on parenting behaviour and attachment, biologically by impacting on self-regulation processes, and through the legacy of the conflict in communities. Together these create adversities for young people increasing their risk of mental illness and thwarting efforts to build peace. The result is a cycle of multiple adversities, under attainment, and continuing community violence.[6]

This report on transgenerational trauma presents a summary of the evidence for the extent of and effects of childhood adversities in NI, and their connection with the Troubles. The impact on the next generation will be discussed. The chapter ends with recommendations for the need for a trauma-informed approach to the delivery of education and health care here, and as an approach to managing the legacy of the conflict. We end by setting out a vision for what "trauma informed" would look like in NI, and the benefits for mental health, peace and prosperity.

Trauma may be passed from one generation to the next through its impact on parenting behaviour and attachment, biologically by impacting on self-regulation processes, and through the legacy of the conflict in communities.

Childhood adversities are known to account for 39.8% of mental illness globally.

KEY RESEARCH

The first epidemiological estimates of mental illness in Northern Ireland (NI), based on psychiatric criteria were provided by the 2005-2008, NI study of Health and Stress (NISHS)[7]. Results showed a high (39.1%) prevalence of mental illness, with long treatment seeking delays. NI had the World Mental Health Survey's highest recorded rates of Post-Traumatic Stress Disorder, ahead of war-hit regions such as Israel and Lebanon, at a yearly cost to the public purse of around £175m.[8] The excess is attributed to the effects of trauma exposure from the years of violence.[9]

Childhood adversities are known to account for 39.8% of mental illness globally.[10] The NISHS revealed that those adults in Northern Ireland who grew up during the 'Troubles' have an increased prevalence of childhood adversities due to traumas associated with the 'Troubles'. The conflict also had an additional indirect impact, since it was related to an increase in other types of childhood adversities such as poverty, family dysfunction and parental mental illness.[11] The literature on childhood adversities typically refers to Adverse Childhood Experiences, or ACEs. Such "ACEs" surveys generally include questions related to family violence, neglect, physical and sexual abuse, as well as parental mental health problems, substance abuse and criminality within the family setting. The number of ACEs experienced is calculated. However, this practice has come under scrutiny recently, with many believing that rather than providing a score, the impact of childhood adversities must extend to consider other factors[12], such as the clustering, severity and duration of adversities.[13]

Whilst a recent report stated that there is no population data of ACEs in NI[14], there is comparable data available from the NISHS.[15,16,17,18,19,20] These studies included questions assessing childhood adversities which are similar to those examined in ACE studies and additionally, economic adversity, physical illness, parental death and other parental loss during childhood. In comparison to the estimate in the SBNI report, that 36% -53% of the NI population have not experienced childhood adversities, the NISHS reports that 68% of the NI population never endured such experiences. However, when childhood adversities were experienced, they had a very detrimental impact on mental health and suicidal behaviour. At 8.6%, economic adversity was particularly high in NI, in comparison to other countries,[21] and there were strong associations with a range of mental health problems.[22]

The elevated rates of post-traumatic stress disorder (PTSD) in the NI population are often attributed to the effects of Troubles-related trauma exposure,[23] however McLafferty et al. [24] found that childhood maltreatment was a greater risk factor. Furthermore, while those who experienced conflict or those who had a mental health problem were more likely to have suicidal thoughts, plans or attempts, individuals who experienced childhood adversities along with these conflict related traumas and psychopathology were even more likely to report suicidal behaviour.[25] Parental mental illness was particularly related to suicidal behaviour, and if childhood adversities could be minimised, then psychopathology and suicidality could be reduced significantly in the population. Specifically, substance disorders could be reduced by 10.4% if family violence was eradicated, mood disorders could be reduced by 10% if sexual abuse did not occur, and suicidality could be reduced by 6.5% by eradicating physical abuse. These findings demonstrate the value of early intervention and prevention programmes for those most at risk and are relevant to efforts to address NI's suicide rate. Childhood adversities rarely occur in isolation and people with multiple adversities were more likely to have a range of mental health problems and suicidal behaviour.[26,27,28] Social networks were protective, and reduced the impact of trauma on mental health, however those who experienced adversity were less likely to have those supportive social networks.[29]

Those people who grew up during the worst years of the Troubles in NI reported the highest rates of neglect and family violence, and this impact on intra-family relationships may have resulted in the trans-generation transmission of trauma. A generation of people, who are now parents, were exposed to both childhood adversities and also trauma as a result of incidents that were part of the conflict. Parental mental illness carries a high risk of mental illness in the child via several mechanisms. Researchers have discovered the potential for biological transmission of trauma in the form of changes to the child's capacity to manage stress and self-regulate. These biological changes can occur in utero, when a mother is exposed to stress, and also in changes to the surface of the DNA pre-conceptually.[30,31]

36%-53% of the NI population have not experienced childhood adversities, the NISHS reports that 68% of the NI population never endured such experiences.

The risk is exacerbated in the case of trauma-related mental illnesses because of the impact of trauma symptoms on parental attachment behaviour, and the capacity of the parent to meet the child's needs in a calm and sensitive manner. The first few years of life are a time when neuroplasticity is at its peak, and the brain's capacity for self-regulation when faced with stressors, is shaped most intensely. This self-regulation promotes adaptive coping and protects against mental illness. The evidence suggests that the emotional impact of trauma can result in poor attachments that will increase the likelihood of mental illness and increase the likelihood of further adversity for the child in the form of family dysfunction, substance use, or even violence. In particular communities this can be accompanied by a community context of ongoing paramilitarism, deprivation, unemployment and educational underachievement. These features amplify the effects of the adversities created by parental mental illness, and in the context of segregation and narratives of hate, can create the conditions for social and political violence. The parenting behaviour that promotes good mental health and coping also promotes empathy, and the capacity to easily understand others' perspectives. There is therefore justifiable concern about the effect of transgenerational trauma on efforts to promote peace.[32]

Evidence suggests that the emotional impact of trauma can result in poor attachments that will increase the likelihood of mental illness and increase the likelihood of further adversity for the child.

In keeping with the theories of transgenerational trauma in NI there is also evidence of elevated rates of mental illness, and indeed suicidal behaviour, in the current generation of young people who were not directly exposed to the worst years of violence. The Ulster University Student Wellbeing Study (UUSWS) commenced in 2015 as part of the WMH consortia's research into student mental health and wellbeing. High rates of mental illness and suicidal behaviour were revealed in the student population. Risk factors included childhood adversities and poor parenting practices. While many of the participants in the NISHS grew up during the Troubles, the majority of the cohort in the UUSWS were born after the conflict ceased.[33,34]

Whilst childhood adversity may, at low levels, promote resilience and provide people with coping skills to draw upon in later years, the high levels in the NI population who are parented by the generation affected by the Troubles constitute trauma exposure which can over time result in toxic stress. Toxic stress in childhood impacts on the child biological stress response systems creating hypervigilance, poor coping skills and behavioural difficulties, which, if not addressed appropriately are conditions that can lead to mental illness.[35]

Trauma informed practice, and trauma-informed "treatments", when delivered in early years and primary school settings, can have a powerful impact on reversing these effects, and reduce the risk of lifetime mental illness and suicidal behaviour.

"Trauma informed" or "trauma focused" approaches to the delivery of care and treatment, or the management of behaviour in a classroom for example, may be viewed as an alternative to the traditional psychiatric model used to conceptualise and understand mental illness and wellbeing. The approach acknowledges the biological impact of trauma on the body and brain, and the potential for trauma to adjust how the whole system responds to stress. It is also a whole systems approach in that it considers the "systems" within which education, care and treatment are delivered and advocates for an understanding of how individuals operate to deliver care within these systems.[36] Trauma informed care includes education and awareness raising regarding the impact of trauma. It also means preventing trauma and the early identification of those who may be affected. Finally, it means the delivery of evidence-informed trauma-specific assessments and interventions. Trauma focused interventions have several key components. They address the impact of trauma on the body which can lead to hypervigilance and an exaggerated stress response, and use therapies which train the individual to self-regulate in response to stress, whilst avoiding stimuli which could potentially activate the stress response. They place importance on the development of safe spaces for young people and prioritise one to one attachment relationships and building trust. For PTSD the National Institutes for Health and Care Excellence recommend trauma focussed Cognitive Behavioural Therapy (CBT) or eye movement desensitisation and reprocessing (EMDR).[37]

The Adaptation and Development after Persecution and Trauma (ADAPT) model may also be of value in the implementation of trauma informed practice in the "post-conflict" context of NI. This module characterises stable societies as having five core pillars which promote psychological well-being and good mental health. These are; safety and security, human bonds and social networks, justice, roles and identities, and world views and belief systems. Conflict and political violence are disruptive to these principles and according to this model, they must be repaired in order to restore community mental health and individual recovery.[38] NI is currently undergoing a process whereby the issues relating to the legacy of the conflict, particularly issues of justice and truth, are being discussed and negotiated. The destabilising impact of this, and effect on those with trauma related mental illness has been outlined by O'Neill and Hamber.[39] A trauma informed approach to managing the legacy of the conflict would incorporate the elements identified above, and importantly adopt a victim and survivor-centred perspective, with due consideration to the impact on the victim, and their journey through the system. In keeping with a trauma informed approach, the institutions should screen people for mental illness and trauma-related conditions and facilitate treatment.

Some work has already been undertaken to guide NI organisations in the implementation of trauma informed care to reduce the impact of transgenerational trauma. For example, Bunting et al[40] outlined the principles of trauma informed care and how it applies to the child welfare system. McLafferty and O'Neill[41] also provided a series of recommendations; which include parenting programmes, and structured programmes to address the impact of co-occurring adversities. They highlight the need for practitioners to enquire about childhood trauma, economic adversity, parental loss and parental mental illness; and advocate a focus on early intervention and prevention. Resilience building is also part of trauma informed practice, and evidence-informed resilience programmes which are founded on sound theoretical frameworks are recommended. Examples include the "Saving and Empowering Young Lives in Europe (SEYLE)" interventions.[42] These need to be delivered in schools and early years settings as a mandatory element of the school curriculum in order to have a broad impact.

Toxic stress in childhood impacts on the child biological stress response systems creating hypervigilance, poor coping skills and behavioural difficulties.

KEY RECOMMENDATIONS

The analyses of the impact of the years of violence in NI on the mental health of the population, has highlighted the effects on those directly exposed, and also the impact on their children. Trauma may be passed from one generation to the next in the form of new traumas of a different nature, created as a result of parental mental illness and substance use in a community context of violence and deprivation. Co-occurring adversities relating to family violence and parental mental illness, are particularly detrimental in the absence of strong social **support networks**. The research findings highlight the need to provide trauma **informed interventions** and care to those who grew up during the 'Troubles', and also the generations since. The approaches and interventions recommended address the underlying pathways of coping and **self-regulation**, which reduce the risk of mental illness and improve self-regulation and adaptive coping in the face of stress. They lead to improvements in empathy, and negotiating skills that promote conflict resolution; and enhance the ability of young people to engage with the education system and achieve their **academic potential**. They reduce the risk of the externalising behaviours that result in suicide and social violence. In summary, a **"trauma informed"** NI is an NI that addresses the mental health impact of the Troubles and supports young people to achieve their full potential in a context of peace of prosperity.

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Chapter 6

Do we need a new policy approach to tackling drugs in Northern Ireland?

Vanessa Gstrein

KEY ISSUE

Drug and alcohol use and misuse represents a costly social and economic burden that demands effective policy responses. Northern Ireland's most recent drug and alcohol policy expired in 2016[1]. Since its development significant new challenges have arisen, particularly in relation to changes in drug use patterns and the emergence of new drugs and dark web drug markets. This chapter sets out some of those issues before presenting evidence-based alternatives to the current criminal justice-led policies which have failed to curb drug use, drug availability or drug-related deaths. A case is made for supporting a paradigm shift to policy focused on health-based outcomes which would directly contribute to the achievement of several key indicators in the Programme for Government, including reductions in health inequalities, crime and preventable deaths.

The use and misuse of drugs in Northern Ireland is a pressing public policy issue. Drug-related deaths among men have doubled in the last decade.[2] In 2015 Northern Ireland's share of UK drug misuse deaths was 3.39%, while NI's population was 2.84% of the total UK population - a disparity of 19%[3] Moreover, the impact of drugs is not spread evenly in the community. The reduction of health inequalities is a key priority area for public health in Northern Ireland with alcohol and drug related indicators being responsible for some of the largest inequality gaps. According to the *Health Inequalities Report 2019*, those living in the most deprived areas are four and a half times more likely to experience drug-related and alcohol-specific mortality.[4] The financial cost of drug and alcohol misuse in Northern Ireland also poses a significant burden, having been estimated to be over a £1 billion per annum.[5]

Responsibility for addressing the harms associated with drug and alcohol use is shared between Westminster and the devolved administrations. The UK government sets the overall strategic direction and provides the legal framework for illicit drugs through the *Misuse of Drugs Act 1971*[6] and the more recent *Psychoactive Substances Act 2016*[7].

The current national policy, *the 2017 Drug Strategy* focuses on reducing demand, restricting supply, promoting recovery and taking global action[8]. The government in Northern Ireland has responsibility for setting and delivering local strategy, particularly in areas of portfolio responsibility such as health, social care and education.[9]

Northern Ireland's most recent drug and alcohol strategy expired in 2016 and has not been renewed in the absence of an Executive and a sitting Assembly. The five year strategy, the *New Direction for Alcohol and Drugs Phase 2* was devised around five pillars: prevention and early intervention; harm reduction; treatment and support; law and criminal justice; and monitoring, evaluation and research[10]. A review of Phase 2 was completed in October 2018[11]. This review focused on outcomes and implementation of the strategy and did not set out proposed future directions for alcohol and drug policy in Northern Ireland.

In the last decade, there have been significant developments that must be addressed by the new policy for Northern Ireland. They include:

- **the increase in drug related deaths;**
- **the challenges posed by new psychoactive substances (NSPs) such as 'Spice', many of which emerged initially as legal alternatives to controlled substances but are now banned;**
- **new sources of drug supply such as web-based illicit drug market;**
- **the threat posed by synthetic opioids such as fentanyl;**
- **complications arising from an increasing trend in polydrug use;**
- **the misuse of pharmaceutical and counterfeit pharmaceutical drugs; and,**
- **an ageing cohort of drug users with complex co-morbidities**

KEY RESEARCH

Challenges to prohibition

The determination of which drugs will be categorised as legal, and which will be illegal, is a reserve power that rests with Westminster. As a signatory to the 1961 UN Single Convention on Narcotic Drugs, the UK has upheld a prohibitionist approach and banned specific drugs such as heroin, cocaine and cannabis, and more recently, the broad category of new psychoactive substances. Despite the dominance of prohibitionist approaches, drug use is increasing world-wide, with an estimate that some 275 million people used an illicit drug in 2016.[12] In the face of the global scale of drug use, and the emergence of hundreds of new synthetic drugs, prohibition is being challenged for its ineffectiveness and for the substantial unintended harms that come with the enforcement of drug prohibition.[13] The United Nations Office of Drugs and Crime's evaluation of a century of international drug control drew particularly attention to the violence that accompanies the illicit drug industry.[14] The complete absence of regulation and manufacturing standards also leads to unsafe supply which substantially increases the risk for drug users and contributes directly to preventable deaths. This issue is at the heart of the current opioid overdose epidemic in North America which has seen the US recording over 70,000 drug overdose deaths in 2017.[15]

The harms of criminalisation

The UK Government's 2017 Drugs Strategy prioritises criminal justice approaches, with the lead agency being the Home Office. This contrasts with the Republic of Ireland where their new national strategy is characterised as a 'health-led response' to drug and alcohol use.[16] Criticism has been levelled at the UK Government's approach by two Parliamentary Committees which published reports in recent months.[17] Both the Health and Social Care, and the Scottish Affairs Committees challenged the Government on its failure to stem the rising tide of drug-related deaths and called on the Government to consider the decriminalisation of drug possession for personal use as one part of a comprehensive approach to drugs that placed priority on public health and harm reduction.

Drug use is increasing world-wide, with an estimate that some 275 million used an illicit drug in 2016.

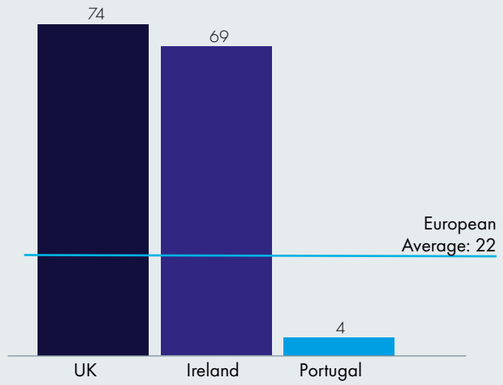
These calls were in line with international and local research evidence on the effects of criminalisation of drug use, which identifies the following issues:

- **Punitive approaches have not decreased drug use nor have had a proven deterrent effect;[18]**
- **It is estimated that globally $100bn is spent annually on law enforcement responses to drug use, and that this effort largely targets low level, nonviolent drug offenders.[19] In the UK, the majority of drug offences relate to possession, and the majority of those to cannabis, taking valuable police time and resources;[20]**
- **Drug policies are often based on the premise that all drug use is dangerous thereby failing to distinguish between drug use and drug misuse.**
  This leads to the blanket application of laws and punitive sanctions that are not related to whether the drug use is problematic or not.[21]
  The majority of drug use does not lead to addiction or long-term problematic use. The UNDOC estimates that 89% of people who use drugs do not experience a drug use disorder;[22] and,
- **Criminalisation of drug user affects employment prospects, access to housing and entrenches stigma which, among other things, deters people from seeking treatment.[23]**

Alternatives to the criminalisation of drug use have been adopted in a number of countries, with the Portuguese model having received considerable attention. Portugal decriminalised the use of all drugs for personal use in 2001 and re-directed funding from the enforcement of law into significant investments in health and treatment services. Portugal now has one of the lowest mortality rates for drug-related deaths in Europe.

Research has found that Portuguese policy has led to reductions in problematic drug use, drug-related harms (deaths and infectious disease transmission), burdens on the criminal justice system, and increased uptake of drug treatment.[24] Ireland's new health-led drug strategy has been influenced by the Portuguese model. Members of both the Scottish Affairs and the Health and Social Care Committees made visits to Portugal as reflected in their respective reports.[25]

Table 1 Drug-induced mortality rate among adults (15-64 years) (latest year available, reported 2019)



Source: EMCDDA (2019) European Drug Report - trends and developments. Available from: http://www.emcdda.europa.eu/publications/edr/trends-developments/2019_en

Expanding public health approaches

Public health approaches to drug use focus on the use of data and evidence to inform policy and practice. The focus on evidence allows for the development of interventions that are tailored for, and responsive to, local circumstances. Health-led approaches can also serve to remove damaging stigma that is compounded by the criminalisation of drug use. Northern Ireland's *New Strategic Direction for Alcohol and Drugs Phase 2* recognised the benefits of harm reduction approaches and made investments in substitute prescribing, needle and syringe programmes and naloxone provision. During the strategy period there were considerable pressures around implementation of these approaches, particularly in relation to waiting times for the provision of substitution treatment.[26]

International research demonstrates the effectiveness of harm reduction interventions in reducing the harms associated with drug use.[27] These can be particularly effective in working with marginalised and at-risk populations who may be experiencing co-morbidities, but also serve to reduce harms to, and the costs borne by, wider communities. Such interventions which should be considered in the context of the challenges facing Northern Ireland, include:

- **Expansion of needle syringe programmes;**
- **Better supported opioid substitution treatment;**
- **Heroin assisted treatment;**
- **Drug consumption rooms;**
- **Improved drug treatment programmes; and,**
- **Specific programmes for prison populations, including focusing on support upon release.**

Given the high levels of prescription drug misuse (both legally and illegally obtained) experienced in Northern Ireland, the new policy must focus on the development of strategies to address this issue.[28]

KEY RECOMMENDATIONS

Drug use is best addressed as a health issue rather than a criminal justice one. Northern Ireland's approach to drug policy should **support recent calls** from the UK Health and Social Care Committee and the Scottish Affairs Committee that policy must be led by public health approaches.

Northern Ireland's most recent drug strategy expired in 2016. The **new drug policy** must be **evidence-based**: this includes subjecting criminal justice approaches to rigorous evaluation as to their effectiveness, alongside public **health interventions**.

Effective evidence-based drug policy would prioritise:

- Consultation on decriminalisation of drug possession for personal use;
- **Improved access** to drug treatment; and
- Investment in proven **harm reduction** interventions: opioid substitution treatment, heroin-assisted treatment, drug consumption rooms, naloxone distribution, needle syringe programmes, and support for prison populations.

A robust drug policy must be underpinned by **quality research** and evaluation to ensure policy continues to be evidence-based. Investment must be made in ongoing research during the course of the strategy as new challenges arise, knowledge evolves and **evidence improves**.

The adoption of an evidence-based, health-led drug and alcohol policy will contribute to the achievement of a number of key indicators in Northern Ireland's Draft Programme of Government, including the reduction of health inequalities. Research shows that punitive approaches to drug use have not had a deterrent effect or contributed to decreased drug use. It is therefore recommended that the balance of investment in this area be shifted to support **health outcomes**, **reducing pressure** on the criminal justice system and focusing support on problematic drug use and its complications through proven public health interventions.

In 2015 Northern Ireland's share of UK drug misuse deaths was 3.39%, while NI's population was 2.84% of the total UK population - a disparity of 19%

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chapter 7

Why is Northern Ireland 'the poor relation' in terms of physical activity?

Marie H Murphy

This paper draws upon an unpublished review of NI policy and strategy on physical activity undertaken by the author in conjunction with Prof Mark Tully (UU), Dr Ruth Hunter (QUB) and Emily Romeril (QUB intern with Department for Communities (DfC) Sport Branch).

KEY ISSUE

Only 55% of adults in Northern Ireland (61% of males and 51% of females) meet current recommendations for physical activity*. There is a secular trend towards inactivity. People in the UK are around 20% less active now than in the 1960s. If current trends continue, we will be 35% less active by 2030. In Northern Ireland, as in other countries, there are inequalities in physical activity, with girls, women, older adults, socioeconomically disadvantaged groups and people with disabilities and chronic diseases, all having higher levels of inactivity.

Sound evidence generated over the past 60 years has shown that regular physical activity[1] reduces the risk of developing, and can help manage, over 20 non-communicable diseases or conditions including heart disease, stroke, type 2 diabetes, obesity, breast and colon cancers and hypertension.

In addition, it contributes to improved mental health increasing mood, wellbeing and quality of life; reducing depression and preventing cognitive decline including dementia.

Physical inactivity is the fourth leading cause of death worldwide[2]. It is estimated to be responsible for one in six deaths and is estimated to cost the UK £7.4 billion annually[3]. In 2002, the DHSSPS estimated that a lack of physical activity was responsible for over 2,100 deaths and 1.2 million working days lost each year[4].

In addition to the individual physical and mental health benefits, increasing population level physical activity has the potential to contribute to the global sustainability agenda by reducing the use of fossil fuels, improving air quality, decreasing congestion and increasing the safety of roads and public spaces. From a societal perspective, increasing physical activity has been shown to increase community engagement, improve social cohesion and decrease loneliness and isolation.

* Physical activity is any bodily movement produced by skeletal muscle expending energy. It can be undertaken for personal transport (getting from A to B) at work (occupational), in or around the home (domestic) and for recreation (sport and leisure pursuits).

Regular physical activity reduces the risk of developing, and can help manage, over 20 non-communicable diseases or conditions.

Given the multiple benefits of physical activity and the high prevalence of physical inactivity it is not surprising that physical activity has been referred to as the "best buy for public health".[5] As a result, most countries have developed comprehensive national physical activity strategies or plans to provide a focus for multisectoral actions at the individual, social and environmental levels. These strategies include targets and timescales for each action and an evaluation framework including surveillance which tracks progress towards the goal of 'more people more active more often'.

The Global Observatory for Physical Activity (GoPA) recommends that every country have a standalone national physical activity plan created and endorsed by the government. The plan should not only endorse the benefits of achieving the recommended level of physical activity, but also encourage the promotion of physical activity and regularly monitor the prevalence of health promoting physical activity. A bespoke national physical activity plan provides a framework for effective and feasible policy actions across multiple sectors and allows shared ownership of cohesive targets by different government departments.

Northern Ireland has not had a standalone Physical Activity strategy since the expiration of the *Be Active Be Healthy – The Northern Ireland Physical Activity Strategy 1996-2002*[6]. Although one of the two key objectives of *A Fitter Future for All 2012-2022* is to increase physical activity levels in line with the UK guidelines, this is an overweight and obesity prevention strategy which does not focus on the importance of physical activity to many other health (mental health, cardiovascular disease, type 2 diabetes, cognitive decline), social (loneliness and isolation) and environmental benefits and does not recognise the potential of physical activity to address 13 of the 17 World Health Organisation's 2030 Sustainable Development Goals. In a similar vein, *Sport Matters 2009-2019* is a strategy for sport and physical recreation which focuses on improving participation, performance and places for sport and active recreation. Neither of these plans adequately capture the multiple domains in which physical activity occurs, nor the range of stakeholders whose cooperation is required to produce a meaningful increase in population level physical activity.

England, Scotland, Wales and Ireland, along with many other countries in the developed world, have bespoke physical activity plans/strategies[7]. Although methodological variance in measurement may account for some of the differences in population levels of physical activity, it is noteworthy that England, Scotland and Wales, who have all had standalone physical activity plans for several decades, report higher levels of participation than Northern Ireland (Table 1).

These physical activity plans provide a roadmap for, and guide actions on, increasing population level physical activity. This is in line with the Bangkok Declaration[8] made by the International Society for Physical Activity and Health (ISPAH) which calls for nations to "develop, resource and implement integrated national action plans" creating a movement towards a single physical activity policy in place of multiple policies[9].

Table 1 Proportion of adults meeting current physical activity guidelines

	All	Male	Female	Source
Northern Ireland	55%	61%	51%	Health Survey 2016/17
England	66%	64%	68%	Active Lives Survey 2018
Scotland	66%	70%	60%	Scottish Health Survey 2018
Wales	58%	64%	53%	National Survey for Wales 2016
Ireland	46%	54%	38%	Healthy Ireland Survey 2019

KEY RESEARCH

In 2018 we conducted an electronic search of the websites of the twelve government departments within the devolved government of Northern Ireland using 'Physical Activity' as the search term. Thereafter, broader search terms were used to minimise the chances of omitting a document. These phrases included, 'fitness; exercise; sport; Physical Education; recreation; physical inactivity; active travel; cycling and walking'. From this search we identified thirty policies which included some form of objective, aim, target, action or indicator relating to physical activity. Following this search, we consulted with contacts from the NI Executive Office and individual government departments to confirm that we had captured all relevant policy documents.

In total thirty policies, strategies, plans or frameworks which include objectives, aims or outcomes relating to increasing physical activity or reducing inactivity were identified. These policies were published by seven different government departments - The Office of the First Minister and Deputy First Minister (OFMDFM), Department for Communities (DfC), Department for Education (DfE), Department of Health (DoH), Department for Infrastructure (DfI), Department of Agriculture Environment and Rural Affairs (DAERA), and the Department of Justice (DoJ). Each policy was reviewed and all aims/objectives, actions, targets and indicators were extracted, Table 2 provides an overview of this policy review.

The findings of this review suggest a fragmented approach to physical activity policymaking which has resulted in a mismatch of unaligned objectives and in many cases a lack of measurable outcomes. In several instances, physical activity was included as part of an objective but was not accompanied by an action or target. The promotion of physical activity appears disjointed with multiple agencies citing the importance of exercise, physical activity and sport but few providing concrete actions, baseline data and realistic time-phased targets.

The move from multiple policies to a single policy has already been achieved in the Republic of Ireland. The *Plan for Physical Activity "Get Ireland Active National Physical Activity Plan (NPAP)*[10]*"* was produced in 2016 and is viewed internationally as a world-class example of a single encompassing physical activity plan. Recreating a single policy out of a range of partial and fragmented policies across departments links to the practice of policy framing, which is an effective way of reviving a policy issue which has previously fallen short of its objectives[11]. The NPAP is due for review in 2020 and is likely to be renewed in 2021 providing a potential window of opportunity for an all-island approach to increasing physical activity.

A fragmented approach to physical activity policymaking which has resulted in a mismatch of unaligned objectives and in many cases a lack of measureable outcomes.

Physical activity has traditionally been regarded as the responsibility of the health or sport sectors but it is clear that increasing activity across multiple domains requires cross-departmental cooperation with health, education, communities, environment, infrastructure, finance, justice and others all being involved and fully committed to creating a more physically active society. Physical activity can and should be integrated into the environment where people live, work, are educated and play but this is only likely to occur if there is a cohesive co-created government-led policy with joined up actions created and owned by multiple stakeholders. Increasing population level physical activity will take time so a physical activity plan requires bipartisan support to ensure continuity beyond changes in government.

Physical activity can and should be integrated into environment where people live, work, are educated and play.

Reversing current trends, increasing population physical activity and reducing the inequalities in physical activity participation requires urgent action. In 2018, the World Health Organisation published a Global Action Plan on Physical Activity (GAPA) 2018-2030[12] recommending a 'systems-based' approach which includes policy actions aimed at improving the social, cultural, economic and environmental factors that support physical activity, as well as individually focused approaches. GAPA 2018-2030 is built around four objectives (creating active societies, creating active environments, creating active people and creating active systems) and 20 policy actions (Figure 1). This global plan could provide a framework for a NI Physical Activity Plan.

Table 2

Department	Strategy Title	Published	Timescale	Physical Activity Related Objectives/Aims	Document Access
Office of the First Minister and the Deputy First Minister	Together: Building a United Community (TBUC)	2011	2011-2015	Strategy will seek to support initiatives and schemes, such as the Game of Three Halves, that use sport as a tool for building good relations and open up sporting facilities to all sections of the community.	https://www.executiveoffice-ni.gov.uk/articles/about-together-building-united-community-tbuc
	Play and Leisure Policy Statement (2009) and Implementation Plan (2011)	2009 & 2011	n/a	• Planning and design to promote play and leisure, making it inclusive and accessible to all. • Promoting the conversion of unused land into viable play and leisure spaces • Promote a greater recognition of the benefits to be gained from play and leisure with parents. • Embedding of play and Leisure Policy within schools and youth provision • Enable children and young people to travel to and access their local play and leisure spaces safely.	https://www.executiveoffice-ni.gov.uk/publications/play-and-leisure-plan-statement-and-implementation-plan
	Government's Anti-Poverty and Social Inclusion Strategy for Northern Ireland	2006	n/a	Additional emphasis for children and young people should also be placed on children's psychological and physical wellbeing. This includes programmes which encourage healthy eating and exercise habits, particularly for those children who are most at risk of poverty.	https://www.executiveoffice-ni.gov.uk/sites/default/files/publications/ofmdfm_dev/lifetime-opp-anti-poverty-and-social-inclusion-strategy.pdf
	Child Poverty Strategy	2016	n/a	• Create the conditions to facilitate at least 36% of primary school pupils and 22% of secondary school pupils to walk or cycle to school as their main mode of transport by 2015. (DRD; PfG commitment). • Invest resources to support initiatives in championing play; greater local access to space for play and leisure; and planning and support for play at a community level. (OFMDFM; DSC Signature Programme, Play and Leisure Implementation Plan). • Pilot a cross-community sports programme aimed at 11-16 year olds from all sections of the community to enhance individual and community development and tackle disadvantage through sporting activities and facilities and promoting equality/improving good relations. (DCAL, OFMDFM; Together: Building a United Community). • Deliver training to school children in relation to walking and cycling skills to encourage active and safe travel. (DRD and the Public Health Agency). • Continue the DE Curriculum Sports Programme in schools which aims to develop the physical literacy skills of the youngest pupils (years 1-4) and instil in them a love of physical activity and sport. (DE; Curriculum Sports Programme).	https://www.communities-ni.gov.uk/sites/default/files/publications/ofmdfm/child-poverty-strategy.pdf
	Active Ageing	2016	2016-2021	Outcome: Older people participate in cultural, educational and physical activity. Age Friendly Environments: promote physical and social environments that support healthy and active ageing.	https://www.communities-ni.gov.uk/sites/default/files/publications/ofmdfm/active-ageing-strategy.pdf
	Programme for Government 2011-2015	2011	2011-2015	Priority 3: Protecting Our People, the Environment and Creating Safer Communities. Priority 4: ...seeks to encourage greater involvement in sporting and pastoral activities to advance social cohesion and integration.	https://www.northernireland.gov.uk/publications/programme-government-2011-2015
	Racial Equality Strategy 2015 – 2025	2015	2015-2025	Increase % of young people who socialise or play sport with people from a different ethnic background.	https://www.executiveoffice-ni.gov.uk/sites/default/files/publications/ofmdfm/racial-equality-strategy-2015-2025.pdf
Department for Communities	Sport Matters	2009	2009-2019	Sport Matters identifies 26 high level targets document identifies 26 high level targets and sets the key strategic priorities for sport and physical recreation over the next ten years and will inform future investment by all stakeholders across the public, private and community/voluntary sectors. The high-level targets are structured to reflect the current and anticipated needs of sport and physical recreation as expressed through consultation. These relate to: Participation, Performance and Places.	http://www.sportni.net/sportni/wp-content/uploads/2013/03/SportMatters.pdf
	Active Living No Limits	2016	2016-2021	• People with a disability are supported by a strong, well-coordinated disability sport sector. • People with a disability lead active lifestyles and have improved health and wellbeing through involvement in sport and active recreation. • People with a disability have equality of choice and consistency of accessible activities and sporting facilities. • People with a disability face 'No Limits' in sport and active recreation.	http://www.sportni.net/sportni/wp-content/uploads/2016/10/Active-Living-No-Limits-Action-Plan-2016-2021.pdf
Department of Education	NI Statutory Curriculum	Current	2017	Physical education (PE) is a compulsory part of the curriculum for all pupils at every key stage, from age four to 16. It is up to schools to determine how much time is devoted to PE in the curriculum, but departmental guidance recommends that they should provide pupils with a minimum of two hours curricular PE per week.	https://www.education-ni.gov.uk/articles/statutory-curriculum#toc-2
	Extended Schools Policy	2006	n/a	Extended schools' activities are designed to support learning, raise school standards and promote healthy lifestyles, enabling schools to work closely with members of the wider community and connect local people with local services. Some examples include ....sport ... and community use of school premises.	https://www.education-ni.gov.uk/sites/default/files/publications/de/extended-schools-policy-document.pdf
	Children and Young People Strategy	2017	2017-2027	Outcome 1 Children and young people are physically and mentally healthy Outcome 2 Children and young people enjoy play and leisure	https://www.education-ni.gov.uk/sites/default/files/consultations/education/Children%20and%20young%20people%27s%20strategy%20%284%29.pdf

Department	Strategy Title	Published	Timescale	Physical Activity Related Objectives/Aims	Document Access
Department of Health	A Fitter Future for All and a fitter future for all - Outcomes framework 2015 - 2019	March 2012	2012-2022	Creating an environment that supports and promotes a physically active lifestyle and a healthy diet. Increasing the percentage of the population meeting the CMO guidelines on physical activity.	https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/obesity-fitter-future-framework-ni-2012-22.pdf
	Service Frameworks (6) for: Respiratory Health and Wellbeing Cancer Prevention, Treatment and Care Cardiovascular Health and Wellbeing Learning DisabilityOlder People Mental Health and Wellbeing	various	various 011-2018	Various including: Physical activity brief intervention training should be provided for Health and Social Care Staff Training should be facilitated for early year's providers to assist them in implementing physical activity and nutrition programmes DHSSPS should develop childcare standards which include the need to provide opportunities for daily physical activity HSC should work with employers to provide opportunities for staff to be physically active The public should be provided with information and support on how to engage in health enhancing physical activity for the prevention of obesity	https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/service-framework-respiratory-2015-18_0.pdf
		2013	2013-2023	• Ensuring all children's and young people's settings provide environments which support good health and wellbeing through, for example, implementation of anti-bullying policies, promotion of healthy eating and physical activity • Ensuring easier access to and sustainable use of publicly owned land including forests for sport and physical recreation • implementation of an Active Travel Strategy Action Plan, providing increased opportunities for sustainable transport options such as walking and cycling and promotion of a number of demonstration projects • Maximise the use of physical assets to increase access to and use of safe, sustainable, health nurturing spaces and places, and opportunities for social interaction in a way that builds health and community and tackles inequalities at a local level for all ages.	https://www.health-ni.gov.uk/publications/making-life-better-strategy-and-reports
	Healthy Child, Healthy Future: A Framework for the Universal Child Health Promotion Programme in Northern Ireland	2010	n/a	Support parents to get the balance right between encouraging play and physical activity whilst minimising the risk of injury.	https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/healthy-childhealthyfuture.pdf
Department for Infrastructure	A Bicycle strategy for NI	2015	2015-2040	• Making urban areas in Northern Ireland more accessible for people using the bicycle; • Improve opportunities for social interaction; • Improvements in public health; • Increase safety for people using the bicycle;	https://www.infrastructure-ni.gov.uk/sites/default/files/publications/drd/a-bicycle-strategy-for-northern-ireland.pdf
	Building an active travel future for Northern Ireland	2010	2010-2020	To put walking and cycling at the heart of local transport, public health and well-being and wider government strategies for the benefit of society, the environment and the economy as a whole.	https://www.infrastructure-ni.gov.uk/sites/default/files/publications/drd/drd-active-travel-strategy.pdf
	A strategic plan for greenways	2016	n/a	• Improve health and wellbeing by creating opportunities for exercise in developing greenways. • Increase the areas and populations that have access to and the use of greenways. • Increase safety for people walking and cycling.	https://www.infrastructure-ni.gov.uk/sites/default/files/publications/infrastructure/exercise-explore-enjoy-a-strategic-plan-for-greenways-november-2016-final.pdf
	Ensuring a sustainable transport future: A new approach to regional transportation	2012	n/a	Improve health by increasing levels of physical activity	https://www.infrastructure-ni.gov.uk/sites/default/files/publications/drd/Ensuring%20a%20Sustainable%20Transport%20Future%20-%20A%20New%20Approach%20to%20Regional%20Transportation%20%28final%20version%2C%20April%202012%29.pdf
Department for Agriculture Environment and Rural Affairs	Focus on the future: sustainable development implementation plan 2011-2014	2010	2011-2014	• Improve quality of life through participating in and accessing cultural and sporting pursuits. • Develop opportunities for new high-quality recreational products in forests. • Improve and enhance accessibility to the waterways and Water-based activity for all equality groups.	https://www.daera-ni.gov.uk/sites/default/files/publications/ofmdfm_dev/focus_on_the_future.pdf
	Northern Ireland Forestry A strategy for growth and sustainability and a strategy to develop the recreational and social use of our forests 2009	2006 and 2009	n/a	Creating a statutory right of pedestrian access to forests, to give greater freedom to cyclists and horse riders to use forests	https://www.daera-ni.gov.uk/sites/default/files/publications/dard/fs-recreation-strategy-2009.pdf
Department of Justice	Sport and Recreation	n/a	n/a	Sport and recreation, including Physical Education, is provided for all individuals who are committed to prison, and is organised so that all prisoners have the opportunity to participate.	https://www.justice-ni.gov.uk/articles/sport-and-recreation

FIGURE 1: Whole-of-Government solutions for Physical Inactivity

Source: World Health Organization. (2018). Global action plan on physical activity 2018-2030: more active people for a healthier world. World Health Organization.

KEY RECOMMENDATIONS

Northern Ireland urgently needs a government-led standalone **physical activity plan** which draws upon WHO recommended best practice to address the growing challenge of physical inactivity. This plan should encompass actions created and owned by **multiple stakeholders** and incorporate a monitoring and **evaluation framework** which includes surveillance of population physical activity to track progress against targets. The review and renewal of the exemplary Irish National Physical Activity Plan 2016-2020 may provide an opportunity for an all-island approach to this shared challenge.

In addition to the physical and mental **health benefits** of **increased activity**, the development of a standalone physical activity plan would contribute to the WHO **sustainable development** goals through multiple government policy objectives such as environment (sustainable transport/active travel), **community engagement**, social cohesion and inclusion.

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Chapter 8

What should be the nutrition priorities for the Northern Ireland healthcare system for both young and old?

Helene McNulty

KEY ISSUES

There are two key nutrition priorities requiring policy decisions – one affecting health in very early life, the other in middle to late life. The first issue can be readily solved by a simple nutrition solution, albeit one that is now over 20 years overdue. The second is more complex and requires interaction of nutrition with other disciplines. The key issues are:

1. **Policy on folic acid for women to prevent NTD – current policy is not going nearly far enough. A population-based policy of mandatory fortification of food with folic acid, (alongside existing policy recommending women to take folic acid supplements before and in early pregnancy) would have important and immediate benefits in terms of preventing neural tube defects (NTD) in Northern Ireland.**
2. **Policy to address dementia in ageing – policy needs to involve multidisciplinary interventions targeted in local communities in middle and late life.**

KEY RESEARCH

1. Folic Acid for women to prevent NTD

Why this is an issue: the evidence

Nearly 30 years ago it was proven beyond doubt that folic acid supplementation of mothers in early pregnancy could protect against neural tube defects (NTDs) in their babies. These are major birth defects occurring as a result of failure of the neural tube to close properly in the first few weeks of pregnancy, leading to death of the foetus or newborn, or to various disabilities involving the spinal cord, the most common form of which is spina bifida. The conclusive evidence that folic acid could prevent NTD has led to clear folic acid recommendations for women of reproductive age which are in place worldwide. To prevent NTD, women are recommended to take 400 micrograms per day of folic acid from preconception until the end of the first trimester of pregnancy. However, implementing this recommendation into practice is problematic.

Folic acid refers to the synthetic form of the B vitamin known as folate. Natural vitamin forms of folate are found in plant and animal foods (e.g. green leafy vegetables, asparagus, beans, legumes, and liver), whereas folic acid is found in the human diet only in fortified foods and supplements (tablets). Folic acid is more bioavailable compared with an equivalent amount of the vitamin eaten as naturally occurring food folates.

Women are recommended to take 400 micrograms per day of folic acid from preconception until the end of the first trimester of pregnancy.

Folate is essential for important biological processes and is particularly important for pregnancy and fetal development, but it plays several other roles in human health through the lifecycle, from childhood to preventing chronic disease in middle and older age, including cardiovascular diseases and cognitive dysfunction.

Current folic acid policy to prevent NTD is problematic in the UK, Ireland and other European countries. For the past 25 years, policy has been based on recommending women to take a supplement containing folic acid from before conceiving until the 12th week of pregnancy. Despite active health promotion campaigns over many years, this approach has had little impact in preventing NTD.[1]

The lack of success of this policy is primarily because women typically start taking folic acid after the period of neural tube closure (i.e. the 3rd to 4th week of pregnancy). For many women, the early period when folic acid is protective against NTD will have passed before folic acid supplements are even started. Thus, folic acid supplementation to prevent NTD is only effective for *individual* women who take their supplements as recommended, but it is not an effective public health strategy for populations because in practice very few women take folic acid at the correct time.[2,3]

The way forward for policy in this area in Northern Ireland

Food fortification is the process of adding essential micronutrients to foods. Food fortification can be conducted on a mandatory (i.e. regulated) or a voluntary basis (i.e. at the discretion of individual food manufacturers). Folic acid fortified foods, like folic acid supplements, are highly effective as a means of optimising folate levels in individual women who are regular consumers of fortified foods (e.g. breakfast cereals).[4]

When folic acid-fortification is undertaken on a population-wide basis via a policy of *mandatory fortification*, it has proven itself to be effective in reducing rates of NTD. Over 85 countries worldwide to date (including the USA, Canada and Australia) have passed regulations for the mandatory fortification of staple foods with folic acid in order to prevent NTD. International evidence shows that rates of NTD have declined by between 27% and 50% in the USA, Canada and Chile in response to mandatory folic acid fortification of food.[5]

In contrast, in the UK, Ireland and other European countries, policy to prevent NTD (i.e. based on folic acid supplementation) has had little or no impact in preventing NTD, despite active health promotion campaigns over many years promoting folic acid. This has resulted in an unacceptably high rate of NTD in European countries, recently estimated to be 1.6 times higher than in regions of the world with mandatory folic acid-fortification policies in place.[6]

Although the UK and Ireland have led the way in Europe in terms of considering folic acid fortification, since 2006, both governments have delayed decisions to introduce a policy of mandatory fortification on the basis of concerns relating to possible health risks. An expert international panel tasked with reviewing all aspects of folate biology, however, recently concluded that that the proven benefits of folic acid fortification would more than outweigh any potential risks.[7] The balance of scientific evidence at this time from two extensive reviews conducted by the UK and Irish governments indicates that there are no health risks at the levels of folic acid being proposed, and the case for mandatory fortification is overwhelming.[8]

Of note, rates of NTD in Ireland are among the highest in the world. Of particular concern is a comprehensive report from the Food Safety Authority of Ireland showing that the incidence of NTD in Ireland has been increasing in recent years.[9] Although voluntary folic acid fortification is permitted in the UK and Ireland and has been beneficial in terms of reducing NTD to some extent, the benefit will only be achieved by those within each population who choose to eat fortified food products. Mandatory folic acid fortification in contrast would reach all women, including those who have not planned their pregnancy.

2. Address dementia in ageing

Why this is an issue: the evidence

Cognitive function in ageing has become a global public health priority as it has important implications for independence and quality of life among older adults. With the prevalence of dementia predicted to triple by 2050, it is important to identify those people at greatest risk of developing cognitive impairment, an early predictor of dementia.

A comprehensive report published in The Lancet recently highlighted the potential for effective dementia prevention through targeted interventions to modify risk factors that could transform the future for society.[10] Despite expectations that ageing populations globally would lead to large increases in the number of adults with dementia, recent evidence from Europe and the United States suggests that the prevalence of dementia in some counties may in fact be stabilising (or even declining), as a result of improved health in middle life and the potential protection afforded by better educational attainment in early life.[11]

Rates of NTD in Ireland are among the highest in the world.

Deprived social environments are known to breed social isolation, psychosocial stress and limited access to resources and health services, all of which can potentially interact with individual susceptibility to cognitive dysfunction. A notable study from Ulster University recently addressed this issue.[12] Teams from Nutrition and Geography & Environmental Sciences at Ulster worked together and with colleagues from Trinity College Dublin, Maynooth University and clinicians from the health services in Northern Ireland and the Republic of Ireland.

The findings of this study, published in the Journal of the American Geriatric Association,[13] were based on novel analysis of data collected as part of our Trinity-Ulster and Department of Agriculture (TUDA) study of over 5,000 older people across the island of Ireland. The study used novel, geo-referenced, address-based techniques to map and link participants to official socioeconomic indicators of deprivation for Northern Ireland and the Republic of Ireland. This was one of the first studies of its kind to use geospatial methodology in a cross-jurisdictional manner to integrate socioeconomic and health data from two nationally independent datasets and two separate health systems.

Intriguingly, the results showed that compared with people in the least deprived areas, older people living in the most deprived areas in Ireland North and South had:

- **spent three years less in formal education as teenagers and young adults**
- **higher rates of smoking and higher alcohol consumption**
- **higher rates of obesity**
- **higher blood pressure**
- **higher risk of diabetes**
- **higher rates of depression and anxiety**

Even after all these factors were taken into consideration in the analysis of the study results, older people living in the most deprived areas were found to be at 40% higher risk of having cognitive impairment compared with a person of the same age living in the least deprived areas. This suggests that societal factors relating to the living environment, such as income inequality and access to resources, may be implicated in the poorer health outcomes.

The way forward for policy in this area in Northern Ireland

Implementing appropriate policy based on dementia prevention strategies and interventions has the potential to transform lives. The recent Ulster University research study shows that older people living in the most deprived areas across the Island of Ireland are at higher risk of poor mental health and cognitive impairment. The findings linking area deprivation with, not only increased risk of cognitive impairment and lower educational attainment, but a range of adverse lifestyle and CVD disease risk factors, points to the living environment as a key component in dementia risk and thus a worthwhile target for efforts to reduce dementia occurrence and disability.

Potential effective dementia prevention through targeted interventions to modify risk factors in communities with the greatest area-level socioeconomic deprivation.

This research has the potential to help shape policy to improve health in older adults in Northern Ireland, generally and specifically in the area of preventing dementia. The findings identify the potential for effective dementia prevention through targeted interventions to modify risk factors in communities with the greatest area-level socioeconomic deprivation.

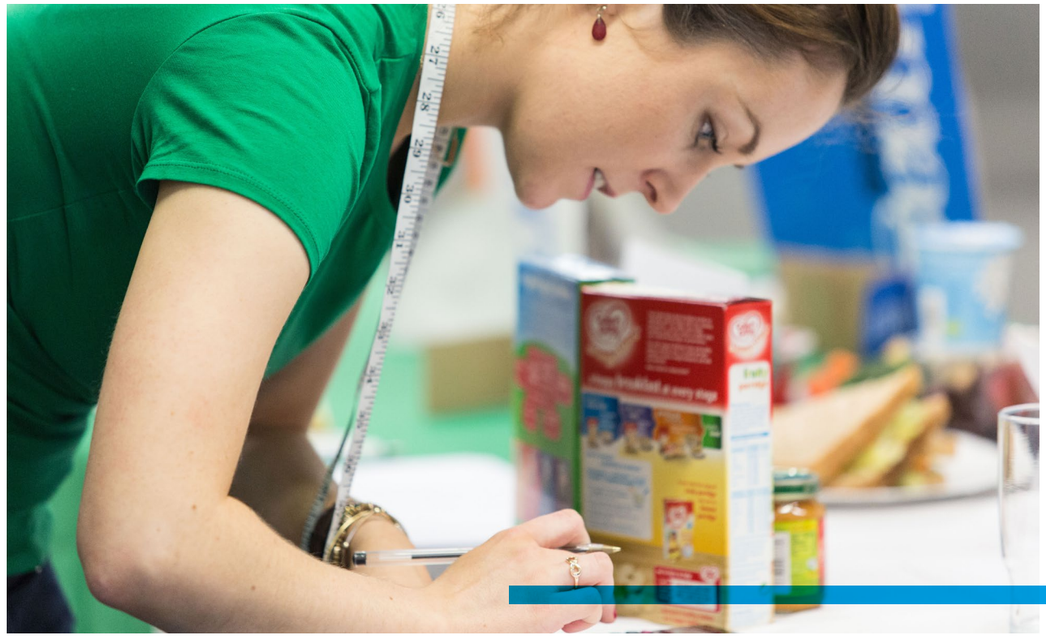
KEY RECOMMENDATIONS

Policy on folic acid for women to prevent NTD:

- Current policy in this area in the UK, Ireland and most European countries involves recommendations for women to take folic acid supplements. This policy is largely ineffective, with powerful evidence showing that there has been no change in NTD over the 25-year period that the current strategy has been in place.
- A policy of mandatory folic acid fortification (in place in 85 countries worldwide) would be highly effective in preventing NTD in Northern Ireland. International evidence shows that wherever such a policy has been introduced, it has proven to be effective in reducing the rates of NTD in that country.
- New policy to introduce mandatory fortification is needed. Because rates of NTD in the island of Ireland are among the highest in the world, this is arguably more urgent for Northern Ireland than elsewhere in the UK.

Policy to address dementia in ageing:

- Future policy to improve health in ageing should involve multidisciplinary approaches in local communities.
- Priority should be given to policy that tackles the inequalities in health in older age through targeting disadvantaged communities. People living in areas of greatest socioeconomic deprivation may benefit from targeted interventions aimed at improving modifiable risk factors for cognitive impairment and risk of dementia.
- Ideally policy should consider the life-course model of modifiable risk factors for dementia recently proposed,[14] whereby efforts to prevent dementia in later life would involve strategies to tackle the early predictors of dementia – better education in early life, better cardiovascular health in middle age.



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chapter 9

What can we do to improve social care in Northern Ireland?

Ann-Marie Gray

KEY ISSUE

Adult social care refers to care and support for people who need it because of age, illness, disability or other circumstances. It ranges from help with essential daily activities, such as eating and washing, to participation in all aspects of life, such as work or socialising. Care can be provided in people's homes, to enable independent living or help with recovery after illness and, if home care is no longer an option, to provide for people to live in supported housing, residential or nursing homes.

There has been much less discussion of the challenges facing social care in Northern Ireland than health care. The strong public affection for and attachment to the NHS has ensured that it has remained firmly on the political agenda but the same cannot be said for social care. Major reviews into the transformations of health and social care systems have focused overwhelmingly on health care. Yet, right from the inception of the services in the 1940s the 'fault line established ... between health care which is free at the point of use and social care which is means-tested, has remained a fundamental source of inequity and unfairness'[1].

Across the UK the social care system is in crisis and publicly funded social care has become a threadbare safety net for those with the highest needs. The crisis is a result not just of increasing demand and the funding cuts of recent years, but of historic policy and funding neglect. There are inequities across the system driven by how services are funded and how individuals' contributions are assessed, the fragmentation of the provider market and access to services and differences in care standards and quality. People are frequently trying to navigate the system when they are at their most vulnerable, often as a result of crisis, finding themselves confronted with a complex system and means tested for their care.

The case for a transformative approach to social care has been made[2] with consensus that muddling through or incrementalism is not an option. Some of the most critical issues are the social care workforce, eligibility for care, and access to timely and appropriate care. Linked to, and underpinning all of these, is the issue of funding.

Across the UK the social care system is in crisis and publicly funded social care has become a threadbare safety net for those with the highest needs.

KEY RESEARCH

Funding of adult social care

Unlike the NHS, adult care and support is not free at the point of delivery. For people requiring residential or nursing care in NI there is not just a test of need but also a test of means. This is also the case in other parts of the UK with the exception of Scotland which removed the means test for personal care for people over 65 in 2002. This means test, and the use of housing assets in particular, is deeply unpopular and perceived as unfair. The Expert Panel reviewing adult social care in NI[3] concluded it was unequitable for people to have to contribute towards the cost of care in a care home yet someone with the same assets could receive domiciliary care for no cost.

It recommended that where a person could contribute to the cost of care they should have to do so regardless of the setting. However, it is unlikely that such an extension of charges would be well received by users or the public, nor is there evidence that this is the best way to proceed. The Northern Ireland Life and Times Survey found little support for the idea of means tested care with the greatest support for care to be provided free at the point of use, paid for by a special tax over the person's lifetime. This preference applied across all income groups[4] and was echoed by members of the NI Citizen's Assembly on Adult Social Care[5]. Interestingly, in an apparently increasingly divided United Kingdom, research by the Health Foundation[6] found that a majority among all sections of the public, and the four countries of the UK, see adult social care as a collective responsibility and would like additional funding for adult social care to be raised in the same way as additional funding for the NHS - collectively and progressively. These are important findings as transformative change requires public endorsement.

Access to publicly funded social care support is shrinking as diminishing budgets have seen services prioritised to those with the highest needs leading to growing unmet need.

Service Provision

Access to publicly funded social care support is shrinking as diminishing budgets have seen services prioritised to those with the highest needs leading to growing unmet need[7]. Users of social care and unpaid carers are bearing the brunt of many of the pressures. A 2019 survey of NI carers[8] shows that around 272,000 people - around 1 in 5 - are providing care for a family member or friend, over 58,000 more than the 2011 Census records show. 30% of carers also have childcare responsibilities for a non-disabled child under 18 and the majority are combining work with caring. As in other parts of the UK, some carers (28%) reported that the care and support arranged by social services had been reduced over the previous year. NI lags behind other parts of the UK in terms of positive policy developments for carers - for example, there have been no measures paralleling the Cross Government Carers Action Plan for England or the increase in the rate of Carers Allowance in Scotland. The current Caring for Carers Strategy is over 13 years old. Effective support is vital but the basis of this has to be user assessments which are carer-blind and a statutory basis for carer assessments with adequate resources to respond those assessments.

Self Directed Support (SDS) is being expanded in NI with the aim of providing greater control for users and a more personalised approach in adult social care. More people are being encouraged to take Direct Payments. A number of concerns about SDS were raised in the report of the Expert Panel on adult social care reform. These include the level of personal budget, limited brokerage support and perceived administrative burden on users. A recent report on the experiences of users of SDS by the Patient Client Council[9] found examples of positive outcomes but reiterates some of these concerns. At this relatively early stage in the roll out of SDS there are lessons for policy makers from experiences elsewhere in the UK particularly with regard to the need for advice and support for users and the realistic concerns users hold about the risks of holding a direct budget in the context of cuts to budgets and workforce shortages. It is useful also to be mindful of research showing that service users tend to be less interested in the structures of care and being able to access different care markets and more concerned about the quality of services they receive and experience.

Social Care Workforce

Across the UK more people work in social care than in the NHS. In Northern Ireland the social care sector supports over 41,000 jobs directly[10], including managers and support staff as well as those people directly providing care. The majority of these jobs (60%) are in domiciliary care where over three quarters of workers are employed by the independent sector.

The figures above do not include workers employed privately by users in receipt of Direct Payments. However, there are major problems recruiting and retaining social care workers. While pay and terms and conditions are more favourable in the statutory sector, overall care workers are among the lowest paid in the labour market. As noted in the Health and Social Care Workforce Strategy, the outsourcing of care to the private sector has led to competition between providers almost exclusively on price resulting in a 'race to the bottom'. Investment in learning and improvements also tends to be more limited in the independent sector[11]. The low status, pay and a lack of investment in care workers has been identified as a major factor creating risks to users' human rights[12].

Most observers believe that better pay is the critical factor in addressing workforce shortages but working conditions are also a factor. Workers often do not get the training and support they need to carry out complex and challenging tasks and there is limited opportunity for progression.

Northern Ireland is well placed to begin to address these workforce challenges as worker registration and prescribed training standards are most advanced. But there remain significant problems with regard to comprehensive information particularly on the independent sector. A priority for action, building on the opportunities created by the care worker registration process, should be investment in a more comprehensive workforce dataset (similar to that which exists in England) which would provide critical information for future planning and investment.

KEY RECOMMENDATIONS

There is no resource neutral option for significantly **improving social care**. There has been **positive progress** in the framing of social care as centred around independence, autonomy and well-being and the idea that people prefer to remain in their own home where possible. However, the public struggle to distinguish between social care and the health services provided free at the point of delivery under the NHS. While devolution has paved the way for some divergence in policy there are **common challenges** across the UK and addressing the fundamental question of how social care should be funded requires UK wide cross party consensus and a political will to commit to radical policies which include **greater investment**. The scale of the crisis and the investment required means this is not something that individuals or the private market can address. There is broad **public support** for a universal social care system. An equitable social care system must be based on pooling risks and sharing costs across society. The need for social care cannot be anticipated and the private market has shown little interest in developing insurance products due to the uncertainty around the costs of each individual's care and the lack of popularity of such products with consumers.

The experience of the Citizen's Assembly in NI shows that the public are capable of understanding the dilemmas and trade-offs facing politicians at every level of government and they should help **shape solutions** for the future. Transformation of the social care system is a vital component of the success of **transforming health service** provision in NI. In the short term the critical issue of the social care paid and unpaid workforce should be an early priority in recognition of the particular vulnerabilities facing social care users. The Programme for Government outcomes based approach could be instrumental to prioritising and **measuring progress** on social care goals but only if there is sufficient emphasis on the processes of care. The current indicator of 'increasing the number of adults receiving social care services at home as a percentage of the total number needing care' has to go beyond this to include the quality and standard of services.

272,000 people - around 1 in 5 - are providing care for a family member or friend, over 58,000 more than the 2011 Census records show.

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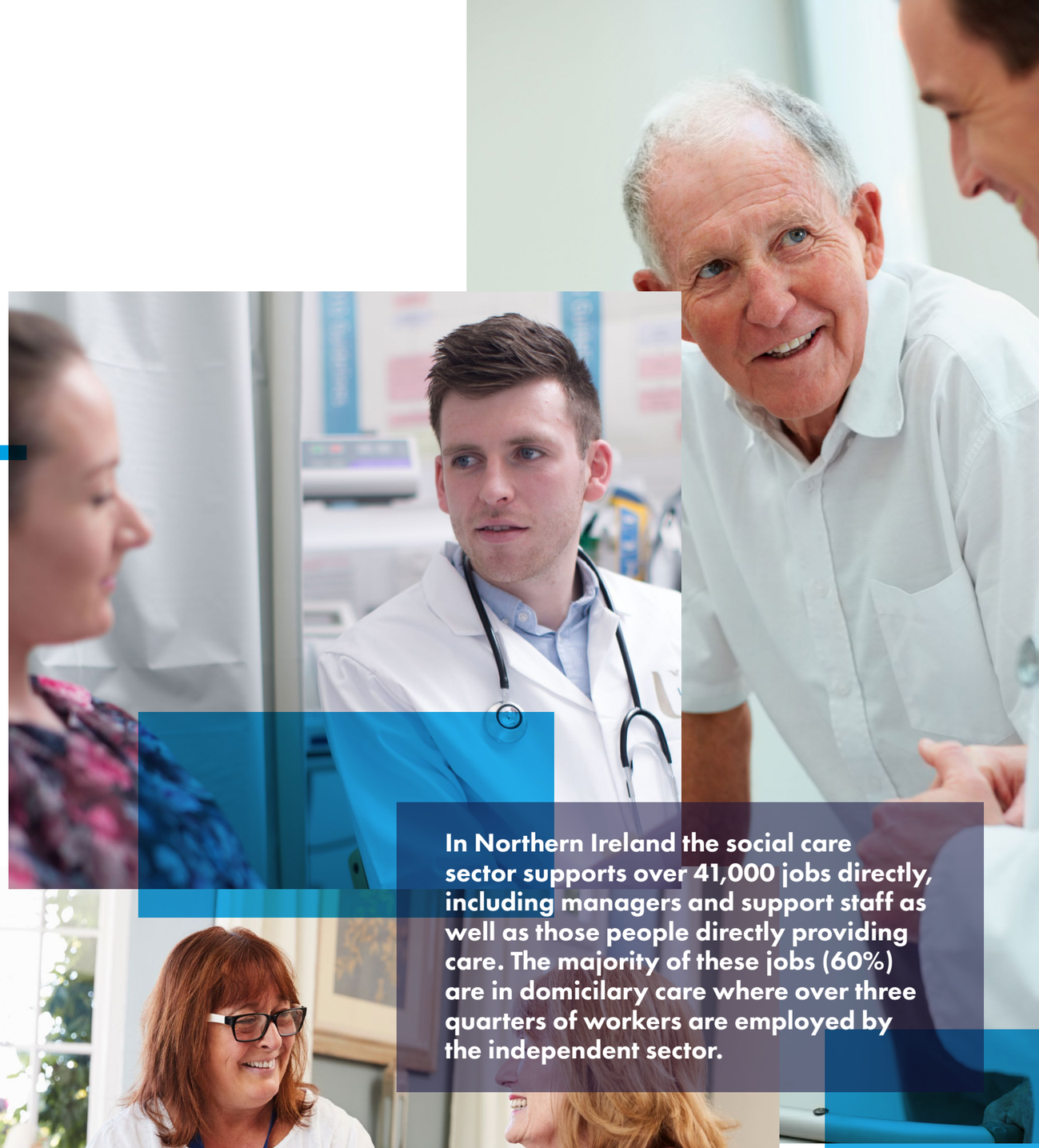

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Chapter 10

What can be done to support older people and their families when moving into a care home?

Assumpta Ryan

KEY ISSUE

The population of the world is ageing and internationally, there is an increasing trend for older people with complex care needs and dementia to reside in care homes.[1] There are approximately 421,000 people aged over 65 living in care homes across the UK.[2] In Northern Ireland, the Health and Social Care Board sets the regional tariff for the 15,897 nursing and residential places in Northern Ireland, leaving limited room for competition between care providers.[3] In many geographical areas, the demand for care home beds exceeds supply.

There are approximately 421,000 people aged over 65 living in care homes across the UK.

Most care home residents have cognitive impairment, often alongside physical and mental health conditions, and are consequently a highly dependent and vulnerable group of people.

Recent media reports highlighting neglect and abuse have heightened public concern for the safety and welfare of older people in these settings. Problems recruiting and retaining staff to work in care homes do little to allay these concerns. Whilst there is evidence to suggest that older people who receive high quality care thrive within the care home environment, there is also a consensus that more can be done to improve quality of life.

The move to life in a care home is very stressful for older people and their families and the need for support and guidance at this time has been repeatedly highlighted in the literature.[4,5] There is evidence to suggest that the level of involvement an older person has in the decision-making process and in the choice of home, plays a significant role in determining the degree to which they will adapt to their new surroundings.[6,7] The move to a care home is also influenced by how an older person perceives this change to their life.

Perceptions of the legitimacy, desirability and reversibility of the move, as well as an individual's perceived control, degree of choice and active acceptance of the placement all have an impact on the experience of the move. Some older people associate care home residency with dependency and mortality,[8] whereas others have reported feelings of relief and improved quality of life following relocation.[9]

Most care home residents have cognitive impairment, often alongside physical and mental health conditions, and are consequently a highly dependent and vulnerable group of people.

This suggests that the distress and deterioration often associated with the move can be decreased by supportive transition practices.

Older adults rarely initiate or engage with discussion about the move to a care home. Instead, decisions are largely made by family members and health or social care professionals.[10] However, there is evidence to suggest that greater involvement in the decision-making process can ease the negative feelings surrounding the move.[11] Residents who were admitted to care homes 'against their will' and those who felt that they 'had no choice' were more likely to experience sadness, depression and anger compared with individuals who relocated willingly.[12,13] In particular, good communication can enhance the move for residents and families, allowing them to feel confident in their decisions, able to ask questions and make suggestions without fear of repercussions. On the other hand, poor communication can lead to uncertainty, worry and anxiety.[14,15]

KEY RESEARCH

Impact of the move on older people

Health and social care practitioners and nursing home staff have a key role to play in supporting older people and their families during the transition to life in a care home. Open communication and shared decision-making involving residents, relatives and staff is central to developing and maintaining positive relationships. Brownie et al.[16] undertook a systematic literature review of 19 studies identifying factors that impacted on residents' transition and psychological adjustment to long-term care. Positive adjustment was reported to be influenced by older people being able to retain personal possessions, continue valued social relationships and establish new relationships within the care facility. This is supported by Ryan & McKenna[17] who highlighted the significance of 'the little things,' in maintaining the dignity and identity of residents and which are often overlooked in care homes. Individuals who are new to the care home environment value a consideration of lifetime rituals, routines and food preferences while also benefitting from maintaining links with their community and creating a new community within the care home environment.[18]

Helping older people and their families to 'find home' in a care home is a major challenge. Nakrem et al.[19] identified ambiguities concerning the nursing home as 1) a home and a place to live 2) a social environment in which residents experience most of their social life and 3) an institution where professional health care is provided and regulated.

Cooney[20] interviewed 61 residents in long term care settings and identified four factors as critical to finding 'home': 'continuity', 'preserving personal identity', 'belonging' and 'being active and working'. More recently, Moore & Ryan[21] interview 48 residents and 44 staff to explore the extent to which residents felt 'at home' in their care homes. The authors found that care homes can and are perceived as home by many residents and the move can be seen as a positive life event. Care home staff with 'knowledge and understanding of residents' life stories, routine and preferences' were central to the concept of 'homely care' but this was difficult to maintain in a restrictive environment with a high turnover of staff. While the importance of standards was recognised by all staff members who took part in the study, they nonetheless felt that too many rules and regulations ran contrary to a homely environment and that the focus on documentation detracted from time with residents.

Several studies have highlighted a lack of privacy, restrictions, limited opportunity for social interaction and regimented practices as major challenges which place care home residents at risk of loneliness and isolation.[22] There is no doubt that institutional restrictions, standardised routines and strict risk management policies can threaten an individual's independence and autonomy. Paddock & Todd[23] argue that when independence is removed from a person's life, they can feel defeated and depressed leading to self-doubt about their ability to care for themselves. Moreover, low expectations can lead to reduced capabilities and can be self-fulfilling, causing deterioration in health and cognitive ability and in some cases, a loss of the will to live.[24] Contrastingly, Koppitz et al.[25] reported that some older adults liked the routine of a care home and were happy that they no longer had to grapple with household tasks but instead enjoyed having staff on hand to attend to their needs.

Several studies have highlighted a lack of privacy, restrictions, limited opportunity for social interaction and regimented practices as major challenges which place care home residents at risk of loneliness and isolation.

Impact of the move on families

The move to a care home not only has a profound impact on the lives of older people, but also on the lives of their families. While the move reduces the physical demands of a caregiving role, it does not necessarily reduce the distress experienced by family carers at such a difficult time.[26] Family members often find it challenging to adjust to the transition as they are unclear of their new roles and responsibilities. Feelings of guilt, regret, sadness and a sense of failing in one's duty all add to the distress experienced by families at this time.[27][28]

The value of maintaining family relationships following the move to a care home, both for residents and relatives has been well documented.[29]

Various studies have recommended the need for residents, relatives and staff to have an open and frank discussion about how to negotiate relationships, roles and boundaries, how to sustain the relationships between residents and relatives and how to value and access carer knowledge and expertise.[30] However, Williams et al.[31] argued that an antagonistic relationship can develop between staff and relatives. Many relatives find it difficult to adjust from their previous role as carer to visitor and struggle to carve out a new role for themselves in the care home environment.[32] Good communication is recognised as a vital element in forming good staff-family relationships and can enhance the move for residents and families, facilitating shared decision making and creating an environment where early concerns can be expressed and addressed before the situation worsens.

Despite evidence of the positive aspects of life in a care home from the perspective of older people and their families, the public image of care homes has been repeatedly damaged by media reports of very poor care and neglect.

KEY RECOMMENDATIONS

Admission to a care home is a major life event and one which requires engagement and preparation by older people and their families. Families need time to consider all their options and health and social care professionals and care home staff have a key role to play in supporting them before, during and after the move. In determining quality of care, the research suggests a need to recognise the extent to which older people actually feel 'at home' in their care home. Although older residents have psychological and social needs, these often remain unmet as a result of a preoccupation with the physical aspects of care or the failure of staff to understand the significance of the 'little things' from the perspective of residents and relatives. The evidence suggests that care home staff may benefit from educational opportunities designed to facilitate a greater emphasis on ways of making residents and their families feel 'at home'.

There is widespread agreement in the literature that care home environments are unnecessarily restrictive. There is a need to move from a 'risk averse' environment to a 'risk aware' one where residents' need for and right to autonomy, independence and choice are upheld with due consideration to potential risk. This can best be achieved through open and honest dialogue between residents, relatives and staff and through meaningful engagement with other key stakeholder such as regulatory bodies and advocacy groups.

The 'My Home Life' Leadership Support and Practice Development Programme' led by Ulster University aims to improve quality of life for people living, dying, working and visiting care homes. Working in collaboration with key stakeholders (residents/relatives/staff, home-owners, AgeNI, RQIA and statutory bodies), this programme develops the leadership skills of care home managers while also translating research into tangible and robust changes to practice.

In doing so, the programme supports government policy and regulatory standards which recommend greater voice, choice and control for care home residents and their families.

Many families wish to continue providing care to their relatives after the placement and it is important that care home staff recognise this in order to provide them with a sense of belonging and attachment to the care home community. Developing caring partnerships is crucial if the resources of care home staff and families are to be maximised for the benefit of residents. However, this is unlikely to occur unless both parties recognise each other's unique contribution and work in partnership to make this happen. It is important that care home staff understand the factors influencing the decision about entry to care and are sensitive to the range of feelings and emotions associated with this transition. It is also important that families are aware of the demands on care staff and that their expectations are realistic as a failure to communicate concerns and anxieties openly from the beginning can lead to greater problems down the line.

Good quality care is best delivered by care home staff who have gained a deep understanding of the resident and a good working relationship with the family. For family members to play as full a role as possible, they need to be involved in the assessment, planning, implementation and evaluation of care. They need encouragement and information to continue their participation in care, if they wish to do so. 'Time' for the resident and the family is the most important contribution that care home staff can make in building and maintaining a caring relationship. This time can be used to discuss problems, thoughts and feelings and to provide stimulating activities for the resident. However, the availability of more time has major implications for staffing levels.

Families need patience and understanding from care home staff who recognise and value their actual and potential contribution to the care home environment. However, families also need to demonstrate sensitivity to staff difficulties and concerns. Improved communication and sharing of information between families and staff has the potential for an improved working relationship that can only prove beneficial to all concerned.

The World Health Organisation advocates that international health systems need to be better organised around older people's needs and preferences, designed to enhance their intrinsic capacity and integrated across settings and care providers.[33] A human rights approach has the potential to recognise and respect the autonomy of older people to be centre stage in decision making processes about all aspects of their care. However, recognising that most older people would prefer to stay at home, due consideration should be given to the needs of family members, many of whom no longer have the psychological or physical ability to continue supporting an older relative who may wish to remain at home and 'age in place'.

Despite evidence of the positive aspects of life in a care home from the perspective of older people and their families, the public image of care homes has been repeatedly damaged by media reports of very poor care and neglect. Such reports are very distressing for current and prospective residents and their families and it is important that examples of best practice are also shared by the media. Improving educational and career opportunities is key to the recruitment and retention of staff with the knowledge, skills and attitudes required to care for some of the most vulnerable people in our society. Equally, a partnership approach recognising and valuing the contribution of residents, relatives and staff to the creation of a 'homely' environment would be a useful starting point in changing the narrative around life in a care home.

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Chapter 11

What difference will health technology make to healthcare in Northern Ireland?

Jim McLaughlin

KEY ISSUE

A new generation of robust healthcare technology solutions are becoming essential to address growing healthcare cost and patient safety challenges due to a global ageing population[1], an increase in chronic conditions[2], global health economics, and increasing need for earlier diagnosis and predictive analysis. Current monitoring techniques are inherently inconvenient to patients, designed without user-needs addressed, produce high false-positive/negative rates, often are not clinically relevant and do not meet the increasing demand for accurate data to aid patient-flow through our healthcare systems. However, practical controlled patient monitoring has been proven to reduce Emergency Room visits by 15%, emergency admissions by 20%, bed-days by 14%, and mortality rates by 45% in the general population[3]. These studies demonstrate the advantages but with improved precision much improved statistics are possible, particularly if such initiatives act as a complete system and address the vision of Healthcare 4.0 which is to deliver more effective and efficient health care services via a digital approach.

Aging populations will drive up the demand for life and health industry products and services and, at the same time, will require economies across the globe to re-invent the way care is delivered and funded. The global population age 60 or above has tripled over the last 50 years and is expected to more than triple again over the next half-century, to reach nearly two billion in 2050. The growth rate for the world's 65+ year-old population is projected to outpace that of the 0-4 year-old segment by 2022, thus increasing demand for life and health sciences industry products and services.

In particular, remote monitoring has been proven to have predictive value in the early detection of heart failure decompensation[4]. Artificial Intelligence (AI), 5G communications and the Internet of Things (IoT) promise to be disruptive technologies in every sector of society, with healthcare being a key interest to many industries applying these technology platforms. We are on the verge of much improved wearables with enhanced AI inspired algorithms, where clinically relevant decision-making will now see an immediate effect on our full spectrum of healthcare and address the need to enhance patient-safety and wellbeing, reducing costs and underpinning the drive towards home-based care and self-management.

Practical controlled patient monitoring has been proven to reduce Emergency Room visits by 15%, emergency admissions by 20%, bed-days by 14%, and mortality rates by 45% in the general population.

This overview will detail the need for the full adoption of our NI Health Innovation strategy that will follow on from NI MATRIX[5] Transforming Your Care and various Department of Health Digital Health initiatives as well as benchmark against national and international government led programmes.

KEY RESEARCH

Technology is reshaping our lives in so many ways, both professionally and personally. In many ways, it is obvious how technology is changing the way we manage and treat health issues; automatic defibrillators, electronic care record systems, wearables, implantables, online record sharing, robotic surgery, scanning and diagnostic tools, alongside biotech developments such as stem cell R&D.

Major recent developments include the Abbott Freestyle Libre, which wirelessly monitors glucose levels via a 2-week arm-positioned pad that has changed the lives of diabetics who had to pin-prick blood samples regularly. Also, FDA has approved the Proteus Digital Health digestible sensor. The ingestible sensor communicates with a wearable sensor patch if a drug is taken, then the information is transmitted to a smartphone or tablet of the caretaker or the patient. We will also soon see a leadless fully implanted 12-year pacemaker within the heart to improve on current pacemakers, and heart-pumps are looking more of a reality.

From 3D printed drugs, to virtual reality for medical training and pain management, right through to using artificial intelligence to root out therapies from molecular databases – one thing is clear, the pace of technological advancement is speeding up, and in this highly regulated industry there is now a real need for policy-makers and regulators to keep pace with this progress in order to allow patients to fully benefit.

Today, the global life-sciences sector is in the midst of significant and rapid change, which presents both opportunities and challenges. Driving this change are supply and demand side pressures, lifestyle choices, longevity, costs and a rise in chronic conditions such as heart failure, diabetes, obesity and dementia. In confronting these realities, traditional ways of working will become outdated. The drive for cost-effective solutions in the Health Service, combined with the regulatory approvals process can mean that uptake is slow.

Our healthcare systems within the UK are currently undergoing significant and rapid change in an attempt to respond to a growing, aging population with increased incidence of chronic illness. This is despite shortfalls in funding within the National Health Service (NHS) expected to reach over £30bn by 2021.[6] Various actions have been debated that may help alleviate pressure, with productivity savings being a key focus. Reduced running costs, shorter length of hospital-stay and development of innovative new models of care-delivery have been suggested as ways to increase efficiency, which is a key element of the UK Governments Ageing Challenge[7].

A step change and better adoption of the digital age is required to create such efficiencies.

New and emerging medical technologies, advances in pharmaceuticals and biological sciences, ageing populations and the rising costs of healthcare delivery are driving major change in regions across the world, and these are now part of a range of strategies in Northern Ireland including Transforming your Care which was initiated in 2011. As a result of this, new global markets are opening and new opportunities are emerging for product-based and service-based Northern Ireland companies to grow even more significantly than in recent years, for clinicians to provide improved healthcare for patients and for researchers to produce findings of value to Life Sciences companies globally.

There is huge potential to better support the adoption and diffusion of innovation, to access patient-data to inform the development phase, and to involve patients in trials and early access schemes for the treatment of chronic diseases, such as heart failure and cancer. The industry is changing, and many countries are driving forward innovative new practices to adapt. NI must do likewise so that we can compete in this challenging environment. At the core of this will be research, innovation, commercialisation and government support.

A May 2018 publication[8] by the Office for Life Sciences reports that the UK is considered a global hub for life sciences, with 5,649 life sciences businesses (the majority (82%) of which are SMEs) with a presence in the UK, generating turnover of over £70bn and employing 240,900 people.

Approximately 123,900 (51% of the industry total) are employed in the Med Tech sector of which 97,300 (40%) are employed in 2,604 Core Med Tech businesses. Within the Med Tech sector, the segment of digital health is the largest, accounting for 10,000 jobs in 491 businesses with a turnover of £1.2bn.

New and emerging medical technologies, advances in pharmaceuticals and biological sciences, ageing populations and the rising costs of healthcare delivery are driving major change in regions across the world.

The report notes "the digital health segment has strong growth potential. The global market for digital health was estimated to be worth £70bn in 2016 and is expected to almost double to £150bn by 2020 with mobile health applications and devices forecast to show the fastest growth". Notably, the digital health segment is cited as being a "relatively young industry with 27% (131) of the businesses incorporated in the last 5 years and 54% or 260 in the last 10 years, this compares with 17% (1,099) and 29% (1,851) respectively for all life science businesses".

Northern Ireland is part of the overall UK Life Sciences sector. The UK is currently a world leader in Life Sciences (pharmaceuticals, medical biotechnology, and medical technology), ranking 2nd in the world after the US. The UK Life Science industry is growing faster than the economy as a whole and is a key source of high-skill, high-tech jobs. R&D expenditure in the industry is valued at almost £5.5bn and life sciences manufacturing accounted for 8% of the UK total (by gross value added).

The strategic importance of Life and Health Science for Northern Ireland has been recognised at the highest level through key strategy and policy documents for the region: Programme for Government (PfG) 2011-15; Economic Strategy for Northern Ireland 2012; Transforming Your Care strategy for Health and Social Care towards more modern and improve health and social care services for everyone; Memorandum of Understanding between the Department of Health, Social Services and Public Safety and Invest NI to drive Innovation and Collaboration in the sector; Economy and Jobs Initiative Task and Finish Group to better exploit the economic opportunities from Connected Health for the health and social care (HSC) sector.

The contribution of Life and Health Science to Northern Ireland plc has increased over the past five years. The excellence of research activity led from Northern Ireland in the area of sensors, diagnostics, respiratory conditions, oncology, diabetes and clinical research is recognised internationally and reflected in the highly rated results from the Research Excellence Framework for Ulster University and Queen's University Belfast. More than 1,000 people are employed in the Centres of Excellence attracting more than £50m in research funding.

The private sector contributes nearly £1bn value to the local economy and is 90% export orientated. It is mainly composed of indigenous Small and Medium Enterprises employing more than 9000 people. Three global leaders (Almac, Norbrook and Randox) in diagnostics, generics, veterinary pharmaceuticals and drug discovery who have developed their own unique supply chains are based in Northern Ireland.

Key medical device companies (Heartsine-Stryker, Armstrong Medical and Bemis) and a wide range of new start-ups, particularly in the diagnostics industry are globally impacting with high growth rates.

In particular there will be opportunities for more targeted and personalised care across conditions including oncology, respiratory illnesses, cardiology, dementia, diabetes, ophthalmology, obesity and atherosclerosis. Delivering on these will require key enabling capabilities including Personalised Medicine, Connected Health, Clinical Trials, Diagnostics and Artificial Intelligence. These are significant areas of opportunity where Northern Ireland can capitalise on recognised areas of excellence.

Key indicators of success that are already rapidly developing with this sector include:

Academia:

- 2014 Research Excellence Framework – UU and QUB achieved impressive life sciences results
- 1,000+ people in centres of excellence attracting £50m+ funding

Public Sector:

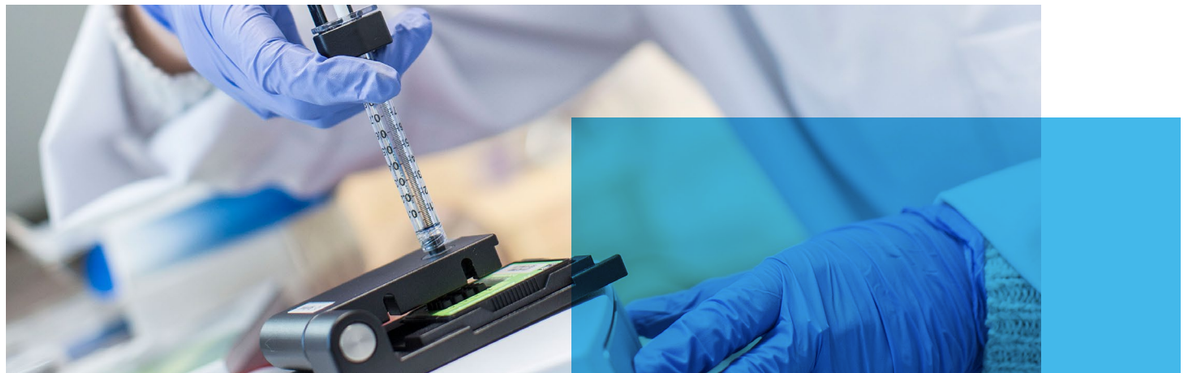
- Every £1 of HSC R&D funding generates an additional £4.14
- Unique integrated health and social care is a positive that has yet to realise a benefit for the sector as a whole

Private Sector:

- 130 mostly indigenous companies employing around 9,000 people – averaging 10% growth per annum in last 3 years
- Highly export focussed sector – around 10% of Northern Ireland exports, growing by average 12% per annum
- £1bn value to local economy and is 90% export orientated

The development of Northern Ireland's LHS sector requires a focused approach that leverages existing strengths while also remaining open to opportunities emerging from outside of Northern Ireland. That approach will take into consideration long term societal trends that demonstrate a significant long-term shift for healthcare including:

- an increasing focus on the need for personalised care and prevention;
- the shift towards a partnership model of care where patients will play an active part in determining their own care and support needs;
- greater focus on prevention, earlier diagnosis and better treatments;
- building the capability to help people manage multiple chronic conditions at once.



One of the key recommendations of the Economy and Jobs Initiative Task and Finish Group (2013) was to establish a Hub to co-ordinate and drive projects and programmes coming out of the overall agreed strategy. The Health Innovation Research Alliance Northern Ireland (HIRANI) has now been set up and has started to fulfil such a role. The UK government has identified this area as a key challenge within its UK Industry Strategy[9] and has identified large funding under an Ageing Grand Challenge. NI intends to grow on its areas of expertise, world-class knowledge and strong industry sector to further develop its already strong global position.

Finally, there are a range of key enabling technologies and processes required to capitalise on the opportunities arising from these demands across sectoral markets. Newly proposed Belfast City Council and Derry City Council City Deals are addressing many of these by establishing new health-based centres of excellence with strong underpinning innovation pathways. These centres, which include digital health technologies and personalised medicine approaches, will act as drivers for strong innovation productivity via clinical based living labs, improved data science strategies and enhanced academic, business and clinical collaboration.

The global market for digital health was estimated to be worth £70bn in 2016 and is expected to almost double to £150bn by 2020 with mobile health applications and devices forecast to show the fastest growth.

KEY RECOMMENDATIONS

It is now obvious that we are entering into the age of Healthcare 4.0 with challenges that need to be urgently met. Key to these challenges is **upskilling and training** of our workforce. In a recent NHS Topol[10] review a main recommendation concluded that the 'NHS organisations will need to develop a **learning environment** in which the workforce is given every encouragement to learn continuously. We must better understand the enablers of change and create a **culture of innovation, prioritising people**, developing an agile and **empowered workforce**, as well as digitally capable **leadership**, and **effective governance** processes to facilitate the introduction of the **new technologies**, supported by **long-term investment'**. This part of the overall **adoption strategy** is as important as the new technology itself.

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chapter 12

How could personalised medicine transform healthcare in Northern Ireland?

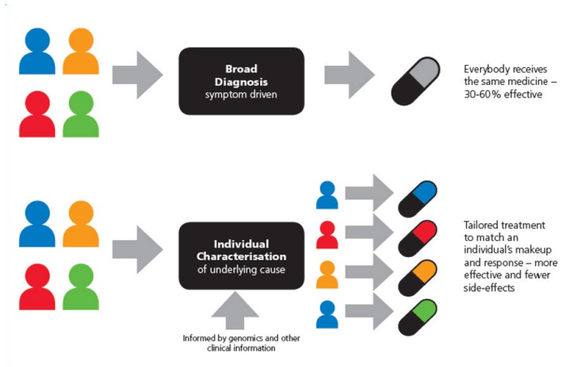
Tony Bjourson

KEY ISSUE

Personalised medicine, also referred to as precision or stratified medicine, is a move away from a 'one size fits all' approach to the treatment and care of patients with a particular condition, to one which uses new approaches to better manage patients' health and target therapies to achieve better outcomes in the management of a patient's disease or predisposition to disease[1].

Most drug development assumes that all patients with a specific condition will respond similarly to a particular drug and patients will generally receive the same first line treatment based on the so-called blockbuster approach to medicine, even though it may only be 30 to 60% effective – a massive waste and sub-optimal treatment. Personalised medicine aims to improve how disease is diagnosed and treated based on an individual's genes, protein profiles and clinical state. Using genomics for diagnostic characterisation, different subtypes of patients with a given condition can be identified, with treatment more accurately tailored to them as depicted in Figure 1.

Figure 1. Comparison of current blockbuster and personalised medical approach (Source NHS England)



Most drug development assumes that patients with a specific condition will respond similarly to a particular drug and patients generally receive the same first line treatment - however this approach may be less than 60% effective.

Personalised medicine is a global priority driven by the practical impact of the completion of the human genome project. Its objective is to ensure the correct patient is treated with the most fitting medicines for them according to their personal genetic profile at the most appropriate time. It also offers new gene therapy approaches to correct genetic errors that cause disease in the first place using new genome editing treatments (e.g. CRISPR) for example.

KEY RESEARCH

Our genome can be viewed as the language used to write the instruction manual for building a human. The English language contains 26 letters combined to construct words and sentences and sometimes we make spelling mistakes that disrupt the meaning of a sentence. All life forms use a universal biologic language written as an instruction manual for how to build, sustain and repair life. That language uses a genetic alphabet composed of four letters A, C, G and T that spell sentences known as genes in the genome of our cells. Our trillions of cells divide, often daily, rewriting their entire inherited copy of 3.2 billion letters in their genomes - a momentous task, and not surprisingly, some mistakes occur when copying the 3.2 billion letters. Such biological spelling mistakes are referred to as single nucleotide polymorphisms (SNPs) or mutations. These changes (SNPs) mostly have no effect, but some cause minor or serious disease. We inherit part of our genome from our mother and part from our father along with many of their unique genetic spellings (SNPs). Our genome is unique to each of us, and it directs our development from embryos through to old age. In combination with our individual life experiences and exposures to chemicals, lifestyle, diet and other factors, our genes determine what diseases we may develop and how we respond to treatment. Exposure to radiation, chemicals, in food or the environment can cause mutations in our body (somatic) cells genome leading to disease. The longer we live, the more times our cells divide, and the greater the likelihood of a mutation occurring. It is possible to now sequence (read) the 3.2bn letters of our genome for a relatively modest cost (<£800) and analyse it to determine what diseases we may likely develop or which drugs we may respond to. Based on that information, we can choose to modify our lifestyles to try and prevent or delay the onset of disease. Personalised medicine not only relies on the reading of our genomes, it requires the collection of large amounts of personal clinical and lifestyle data supported by underpinning technologies such as consumer apps, digitally enabled wearables, and imaging. This approach generates massive amounts of data that needs specialist data storage, data analytics skills and biomedical knowledge to interpret it. This "big data" and its analyses is the bedrock of personalised medicine and the sector requires the interaction between medicine, genomics, data analytics, and artificial intelligence disciplines**.**

In pursuit of personalised medicine, the UK 100,000 Genomes Project is completing the sequencing of the whole genome of 70,000-100,000 people with rare diseases and cancers with regional recruitment coordinated by the Northern Ireland Genomics Medicine Centre[2]. Highlighting its importance, plans to undertake whole genome sequencing of all children at birth to check risk of genetic diseases and offer "predictive, personalised" care was announced in November 2019 by Matt Hancock (UK Health Secretary)[3]. The Academy of Medical Sciences also highlighted the need to embed genomics and personalised medicine into the clinical education curriculum for all healthcare professionals, and stated that the NHS needs to adopt a multidisciplinary approach and include all staff in the patient pathway - from geneticists, bioinformaticians, nurses and clinical specialists.[4] Regionally, since 2013 personalised medicine research and teaching has been strongly supported by Ulster University's Northern Centre for Stratified Medicine[5] based at C-TRIC[6] at Altnagelvin Hospital who are undertaking large scale genome sequencing for personalised medicine, and in 2019 Queens' University' Centre Precision Medicine[7] was launched, all working in partnership with the NHS and local industry[8].

The NHS needs to adopt a multidisciplinary approach and include all staff in the patient pathway - from geneticists, bioinformaticians, nurse and clinical specialists.

Figure 2. Hospital and Primary Care Prescribing Costs £0.66 Bn/ Year (2018)
(2013 to 2018 - Northern Ireland)

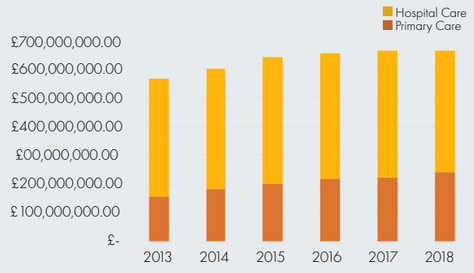
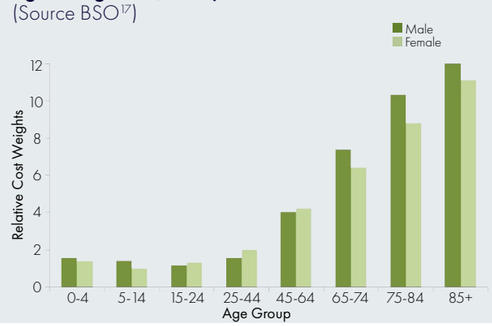


Figure 3. Prescribing cost index by age and gender, 2018/19
(Source BSO[17])



The £72 per head differential in Primary Care Prescribing cost between England and Northern Ireland may reflect an increased disease burden in Northern Ireland or it may be more likely to occur because prescriptions are free in Northern Ireland but not in England. It is widely accepted that projected increases for healthcare render it unsustainable, with policymakers facing difficult choices regarding patients' access to care and medicines.

AGING POPULATION

The problem is driven partly by an increasing aging population due to medical advances that has allowed us to live longer, but longer with more chronic diseases and increased treatment burden. In the UK there are 1.4 million people aged >85, projected to increase to 1.9 million by 2020 and to 3.5 million by 2035, more than doubling over 25 years[12]. The over >65-year age group is by far the largest and most expensive users of the health service as they suffer more chronic disease (Figure 3). Two or more diseases occurring simultaneously in an individual is referred to as multimorbidity which increases with age necessitating multiple treatments.

MEDICATION - THE MOST COMMON TREATMENT

The number of prescribed medications increases with multimorbidity as we age leading to a prescribing cascade and polypharmacy. Polypharmacy refers to the concurrent use of multiple (usually more than five) medications by one individual. Among patients aged 65 years and above, 39% received 1-5 medications; 44% received 6-10; and 14% received more >10. Polypharmacy is associated with increased incidence of adverse drug reactions (ADRs) and avoidable medication-related hospitalisations, accounting for 10% of hospitalisations in the UK, and 8.6 million hospitalisations per year in Europe.[13] In addition, up to 10% of hospital-based patients also experienced an ADR as a consequence of in-hospital prescription medications.[14] Polypharmacy can be therapeutically beneficial (appropriate polypharmacy) or problematic (inappropriate polypharmacy). Appropriate polypharmacy is defined as prescribing for a person for complex conditions or for multiple conditions in circumstances where medicines use has been optimised by medication review and where the medicines are prescribed according to best evidence.[15]

Inappropriate polypharmacy can occur if medicines are prescribed without good evidence, or if (considering the person's views and preferences) the risk of harm from treatments is likely to outweigh the benefits. Polypharmacy is hazardous because of interactions, the demands of medicine-taking (pill burden) can be unacceptable to the person causing lack of compliance; or medicines may be prescribed to treat the side effects of other medicines when alternative solutions are available to reduce the number of medicines prescribed.

In many cases a patient may be on 10 or more concurrently prescribed medications and identifying drug-drug and drug-disease interactions are at the limits of what is possible during a short GP or medicines review consultation. In Northern Ireland community Pharmacists are paid a fee (approximately £28) to undertake a very limited number of medication reviews[16] for a limited number of the high-risk patients, with numbers of reviews capped per practice, and insufficient time to undertake appropriate medication reviews and lack of appropriate computational aids – this needs to dramatically change not only for current practice but in particular if genomics based decisions are to be included as part of the prescribing practice.

There were 41.8 million prescription items dispensed in Northern Ireland in 2018/19 (data for primary care only). (relationship between age/gender and prescribing cost in the form of a 'relative cost index). Figure 3 shows the relationship between age/gender.

In many cases a patient may be on 10 or more concurrently prescribed medications and identifying drug-drug and drug-disease interactions are at the limits of what is possible during a short GP or medicines review consultation.

THE CLINICAL AND ECONOMIC NEED FOR PERSONALISED MEDICINE - UNSUSTAINABLE WASTE

IN ENGLAND (2017-18)
NHS MEDICINES COST
£18.2 BILLION
AN INCREASE OF 39.6% FROM 2010-2011[9]

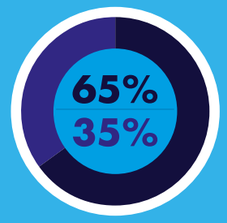
IN 2017-18 HOSPITAL PRESCRIBING COST INCREASED BY
10.8%
ON THE PREVIOUS YEAR TO £9.2 BILLION, COMPARED WITH A DECREASE OF 1% IN PRIMARY CARE[10]

308,200
PEOPLE AGED 65 OR OVER IN NORTHERN IRELAND (16.4% OF 1.8 MILLION)[11]

OVERALL, HEALTH CARE CONSUMED 44%
£5.4
BILLION
OF THE £12 BILLION OF THE NORTHERN IRELAND BUDGET ALLOCATION IN 2019

5.5%
IN NORTHERN IRELAND MEDICATION COSTS CONSUME APPROXIMATELY £0.66 BILLION (5.5%) OF THE HEALTH BUDGET

£234
PRIMARY CARE PRESCRIBING COSTS **£162** SPEND PER HEAD IN ENGLAND COMPARED TO **£234** SPEND PER HEAD IN NORTHERN IRELAND



PRIMARY CARE AND HOSPITALS PRESCRIBING ACCOUNTING FOR **65%** (£0.42 BILLION) AND **35%** (£0.24 BILLION) OF THE TOTAL PRESCRIPTION MEDICATION SPEND RESPECTIVELY (SEE FIGURE 2).

THE DRUGS DON'T WORK

The serious problem of waste is further compounded by the current blockbuster approach to drug development that assumes all patients with a condition respond similarly to a drug. Similarly diagnosed patients generally receive the same first line treatment that is frequently only 30 to 60% effective.[18] The fact that most prescription medications are not effective for possibly 30-70% of patients treated needs urgently addressed. Even worse, some prescription drugs cause harm due to adverse drug reactions (ADRs) and 5-10% of hospitalisations are medicine-related.[19] A new generation of biologic-based drugs are sometimes prescribed to treat specific cancers, arthritis and cystic fibrosis that are very effective but only in a subset of patents. For example, biologic-based drugs used to treat rheumatoid arthritis are the among the most expensive prescribed medications, with patients treated for up to 6 months common practice before their lack of clinical efficacy is recognised and treatment is stopped or switched. Personalised medicine is not only relevant for prescription medication optimisation, it has utility also across many clinical areas and surgical specialties with potential for modification of treatment of e.g. fracture patients depending on bone health as well as predicting the course of scoliosis by early molecular diagnosis facilitating targeted treatments.

So a trial and error approach to prescribing is evident albeit informed by outcomes from clinical trial population-scale statistics. The National Institute for Health & Care Excellence (NICE) publish guidelines based on numbers needed to treat (NNT) to assist doctors, pharmacists and patients in making joint prescribing decisions. The NNT measures the effectiveness of a treatment and it is the average number of patients who would need to be treated for one patient to benefit compared with a control in a clinical trial.[20] Published Drug Efficiency[21] NNT tables provides trial population and duration information. The most frequently prescribed drug to reduce blood pressure and lower heart attack risk is statins, and the NNT for a statin is more than 400 for primary prevention of a heart attack in low-risk patients eligible for the treatment.[22] Thus 400 people would need to be treated for just one person to avoid a cardiac event.[23] This is but one example of the current trial and error nature of current prescribing practice, and waste of money that could be avoided through the implementation of a personalised medicine approach.

Among patients aged 65 years and above, 39% received 1-5 medications; 44% received 6-10; and 14% received more >10

KEY RECOMMENDATIONS

Multiple reviews of care delivery in Northern Ireland have provided recommendations for improving the management of healthcare and addressing **medicines optimisation**, including the Transforming Your Care Report[24], the Bengoa Report[25]; the Health and Wellbeing 2026-Delivering Together Report[26]. Initiatives **involving pharmacists** working alongside GPs was announced with a plan to have 300 primary care-practice based pharmacists in post by 2020 to assist GPs and improve the **safety of prescribing**, and to give GPs more time for patient consultations. With over 8.6 million avoidable medication-related hospital admissions in Europe each year due to adverse medication reactions[27] there needs to be a **significant expansion** of medicine reviews informed by genomic data. Clinicians and patients are faced with challenging decisions when deciding which medications will provide benefit as recommended by a diversity of guidelines, and this will be further compounded by the availability of genome data on all patients. The increased availability of individually **targeted treatments** should reduce waste, enable cheaper more representative clinical trials, but individualised targeted medications will be just as expensive, with the same major dilemmas: who or what benefits is different for the individual versus society generally. To **reduce waste** and to enable the **realisation of the opportunities** presented by personalised medicine, new clinical decision tools need developed and adopted by the NHS, and there is a critically important need to incorporate **genomic education** as a core component in all clinical **education pathways** to drive more **evidence-based diagnoses**, treatments and medicines optimisation in the NHS.

In the UK there are 1.4 million people aged >85, projected to increase to 1.9 million by 2020 and to 3.5 million by 2035, more than doubling over 25 years.

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Chapter 13

What sort of education do we need for our healthcare system in Northern Ireland?

Louise Dubras

DECLARATION

This piece is written unashamedly from a General Practice and medical perspective.

KEY ISSUE

The global population is growing and ageing and demonstrates increasingly complex multimorbidity: From 2016 onwards the global number of over 65 year olds exceeded the number of children for the first time in history, and the mismatch between their numbers is set to increase.[1] This pattern is similarly seen across the United Kingdom, but the 2016 report "Systems, not Structures- Changing Health and Social Care" revealed that Northern Ireland shows the greatest growth of the population of over 85 year olds at 43.1% between 2004 and 2014.[2]

Non communicable disease accounts for by far the greatest burden in our population with examples being:

- **The rate of disability in the over 85s of Northern Ireland at 67% compared to only 5% in the population of younger adults;**
- **The number of people living with dementia in Northern Ireland due to increase to 60,000 by 2051;**
- **Two thirds of all acute hospital beds in Northern Ireland are occupied by patients over the age of 65.[3]**

From 2016 onwards the global number of over 65 year olds exceeded the number of children for the first time in history.

Our society now faces the challenge of Multimorbidity - individuals rarely suffer from a single long-term condition, and frequently we see patterns of morbidity.

The Bengoa report also states that in Northern Ireland:

- **1 in 5 people have a long-standing health condition;**
- **60% of people are overweight (37%) or obese (23%);**
- **Almost one in five adults shows signs of a mental illness; and**
- **10.3% of the population claim Disability Living Allowance.**

Furthermore, our society now faces the challenge of Multimorbidity - individuals rarely suffer from a single long-term condition, and frequently we see patterns of morbidity with a single individual living with Type 2 diabetes, obesity, cardiovascular disease and osteoarthritis as an example. The evolution of medicine over the last 50 years has seen the erosion of the "generalist" role and the development of increasing "sub speciality" healthcare teams in hospitals, with consequent fragmentation of the delivery of care, and failure to care for the whole patient. Even though the recent move to deliver more whole person care in the community through MDTs is welcome[4], this continued pattern of delivery in secondary care has not improved outcomes or experiences for patients. The four Chief Medical Officers of the United Kingdom have recently made a welcome and urgent call for a return to Generalism as a way of addressing the challenges presented by the rise of Multimorbidity.[5]

Data on health inequality in Northern Ireland is also revealing, with men in the least deprived areas living on average 7.5 years longer than those in the most deprived, with the difference being 4 years for women. In the most deprived areas, 30% of people report a mental health problem, double the rate in the least deprived areas; and suicide rates (already the highest in the UK) are higher in the most deprived areas.[6]

Taken overall, this information demonstrates that Northern Ireland has a growing population with complex health needs. Despite the high number of hospital bed occupants being over the age of 65, most medical care is not provided in a hospital, but in the community.

The workload of General Practice in the UK has increased with the consultation rate increasing by 10.5% between 2007-8 and 2013-14, with the consultation rate highest in over 85-year olds.[7] Their Lancet study looked at 101 818 352 consultations of GPs and practice nurses, and together with the rising consultation rate also demonstrated an increasing duration of consultations, such that over the time period of the study there was an overall increase in workload of 16%. In simple terms, GPs are doing more.

KEY RESEARCH

A recent review of Medical School places in Northern Ireland outlined the age and gender balance of doctors in Northern Ireland, their current career pathways, the vacancy rates in a wide range of speciality training programmes and the need to grow the medical workforce by 3.8-4% per year over the coming 10 years in order to keep pace with the demands required by this growing, ageing population. It concluded that a minimum of 100 additional medical school places were required as soon as possible, with a recommendation that this number be reviewed within five years.[8] Certainly[9] at present, Northern Ireland is ranked 3rd of 4 in the number of doctors per head of population in the United Kingdom, with 3.47 doctors per thousand population compared to a mean of 3.76 per thousand.[10]

The situation is further highlighted by the stark figures for spend on hospital locum doctors, which rose by 190% between 2011-12 and 2017-18, from £28.4m to £83m. This spend of £83m represents some 3% of the overall hospital budget, but underlying this are subtler issues such as continuity of care, and reduced morale of doctors.[11]

A minimum of 100 additional medical school places were required as soon as possible.

The British Medical Association views the employment of locum doctors as an indicator for consultant post vacancy rates, and in 2019, this is regarded as 15%. The current locum spend in the Western Trust is 22% of the total medical pay bill.[12] These figures make no reference to General Practice, where locums frequently cannot be sourced, and where practices are closing because of recruitment difficulties. There has been a reduction in the number of GP practices in Fermanagh from 18 in 2016 to 10 in 2019, and a reduction in the number of GPs from 44 to 35 in the same time period. Again, in simple terms, fewer GPs are trying to do more.[13]

The morale of the NHS workforce is noted to be low: healthcare professionals are under increasing pressure delivering care to patients with complex needs whether in primary, secondary or community care settings. The more vacancies exist, the more the existing workforce are under pressure, and increasing numbers also report taking time off work with stress related problems, and this is across the entire workforce, not just doctors.[14] Junior doctors tend to take breaks in their training after Foundation years because of the pressure they experience, and other doctors plan to reduce their hours or leave the NHS altogether.[15] Starling[16] points to the value of Multidisciplinary teams as one innovative approach to supporting healthcare professionals and delivering care to patients.

Northern Ireland has committed to funding and implementing such Multidisciplinary teams in General Practice including Pharmacists, Social Workers, other Allied Health Professionals, Physician Associates and Advanced Nurse Practitioners[17], and The Royal College of General Practitioners (RCGP)[18] welcomes the development of the Multidisciplinary team, whilst advising a cautionary note that GPs must be adequately resourced and supported to integrate these new professionals into the team, and to lead these teams. Furthermore, the RCGP do not see the expansion of the wider team as a substitute for increasing the numbers of GPs.[19]

GPs must be adequately resourced and supported to integrate these new professionals into the team, and to lead these teams.

So what about Patient Outcomes in the context of the skill mix and morale of the workforce, and the provision of continuity of care? The World Health Organisation (WHO) cites extensive evidence that patient outcomes are best where the workforce can provide person-centred care, and continuity of care. The latter is not necessarily from the same individual, but healthcare records must enable safe accurate and timely transfer of information from one carer to another.[20]

This is challenging when the time available for each consultation is constrained. The WHO also notes that the morale of the healthcare worker improves when they are able to provide person-centred care; yet the more time pressure the clinician faces, the less patient-centred they are likely to be; and a vicious circle develops.

Increasingly too, health professionals recognise that the traditional "biomedical model" of healthcare is no longer fit for purpose, and that the rise of non-communicable disease requires increasing input from public health and the development of a "social prescribing" approach.[21]

The development of the role of the Physician Associate (PA) is seen as one way to ameliorate the workforce crisis in the United Kingdom. A PA works "in conjunction with, and complementary to, the existing medical team"[22]; and the Royal College of Physicians notes the value of the PA providing continuity of care in a ward or department of a hospital where junior doctors in training tend to rotate in and out of particular settings. PAs however have a limited scope of work and cannot currently prescribe. Whilst invaluable providers of healthcare, there remains an ongoing need for doctors to lead these diverse clinical teams and manage the complex multimorbidity referred to at the start; and to manage the decision making and concomitant risks associated with providing this complex care. We also face a technical revolution as increasingly we and our patients interact with Artificial intelligence and robots[23], and we have ever more sophisticated data to enable us to provide ever more personalised care to patients. We face global challenges such as climate change[24] and the emergence of new pathogens such as Novel Coronavirus[25]. Medical and health professions educators must therefore structure curricula in such a way as to enable students to learn to be caring competent generalists, capable of working flexibly in a wide variety of settings, with the emerging technology they require, yet still able to deliver the humane and human whole person care that patients will always seek from them.[26]

The next question is how and where to educate these doctors and clinicians. All health professionals must learn from patients, and I have demonstrated that patients are diminishingly in hospitals and increasingly in General Practice and the Community. Students also need to learn about the Human Factors that shape their practice[27] alongside the more traditional requirement for learning communication, teamwork, shared decision making, and the nature of leadership. This can only be accomplished when those students learn together in the community; and this is when we see how the impact of an historic educational model risks compromising our ability to deliver a future-focused workforce.

Medical education was traditionally centred on hospitals and funds were identified to support the education of those doctors in the hospitals, with General Practice seen as an "optional extra" which received very limited funds. Still there is lack of funding parity between hospital and community and general practice[28]. To shift medical education from hospital into community settings means taking money from the former, and in a climate of financial constraints, that is not popular.

KEY RECOMMENDATIONS

Whilst recognising the essential contribution of all members of the clinical workforce, there remains the (at times) uncomfortable fact that we need more doctors, globally, in the UK[29] and in Northern Ireland[30]. We need those doctors in General Practice: can we grow GPs? The evidence suggests that this is possible, although medical schools cannot mandate their graduates' career paths. Taking medical students into **Graduate Entry programmes** and ensuring that a significant proportion of their learning takes place in General Practice seems to increase the likelihood that those students will choose General Practice careers[31].

It is imperative that Northern Ireland's universities are enabled to deliver a **diverse local healthcare workforce** for the 21st Century. To do that, their **continued partnership** with Health and Social Care must be further enabled, whilst recognising that increasingly, care and interventions are provided by a wide range of organisations in our communities.

There should be parity of **educational funding** for all healthcare professionals, so we move beyond the current "two tier" value accorded to medical education over that of our other essential health care professionals. Community and General Practice settings require sufficient **infrastructure** to deliver **authentic education** for the range of health professions education, and those delivering this education need to be assured adequate protected time to prepare, teach and assess learners.

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Chapter 14

Conclusion: Key Recommendations for Consideration

Cathy Gormley-Heenan

Our contributions on health, equality and the economy have considered the context in which health policy is made, the costs and opportunity costs of health policy decisions, issues of health inequality, mental health, transgenerational trauma, drugs, nutrition, physical activity, adult social care, technologies, personalised medicine, and healthcare education.

Although wide-ranging in content, they are connected in the scale of their ambition to ensure better outcomes for patients and a better health and social care environment for everyone.

They make concrete suggestions and policy recommendations which, if implemented, would go some serious way to addressing the aspirations as set in the New Decade, New Agreement (NDNA) document and our previous programme for government.

To summarise, we have distilled the various contributions down to 10 key recommendations:

10 Recommendations

Chapter 15

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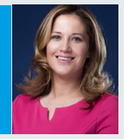
We are currently raising funds to enhance our world-class research in the following areas:

Pancreatic Cancer

Professor John Callan's award-winning microbubble research is paving the way for more effective pancreatic cancer treatment. Professor Callan and his team were winners in the Life and Health Sciences section of Invent 2018.

Pancreatic cancer survival rates have not improved in the last 40 years

Stroke Services



A recent report by **Dr Niamh Kennedy** 'Struggling to Recover' developed in partnership with the Stroke Association has been used by government to feed in to the reshaping of a new stroke services strategy looking at the long-term care and support of stroke survivors in Northern Ireland.

There are currently over 1.2 million stroke survivors living in the UK

Diabetes

Professor Peter Flatt is an internationally respected authority in the field of regulatory peptides, glucoregulatory drugs and experimental diabetes research, earning him the accolade of No 1 insulin researcher in the UK.

Diabetes costs the NHS more than £27million a day

Childhood Cancer

Dr Kyle Matchett leads the only group of researchers working on childhood cancer in Northern Ireland. He is currently working on several research projects aimed at finding new and kinder ways of treating children suffering from acute myeloid leukaemia.

Incidence rates of acute myeloid leukaemia have risen by 29% in the past 25 years

Whatever you choose to support, your gift will play a huge part in tackling today's global challenges and realising tomorrow's breakthroughs.

If you are interested in hearing more about any area of our work, please contact Caroline Armstrong, Deputy Director (Fundraising) in the Development and Alumni Relations Office at c.armstrong1@ulster.ac.uk or 02895367513

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We at Ulster University have asked ourselves the important questions that need to be answered in terms of health policy for Northern Ireland and have presented them here as a series of question-based chapters, reflecting the key issues, key research undertaken and key recommendations for consideration.

We've brought these various recommendations together at the end of this report as our contribution to the current policy debate on the future of health and social care policy in Northern Ireland.

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